Creating a Collective Narrative with Caregivers of a Family Member with Dementia

by

Kirsten Maier

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Department of Educational and Counselling Psychology and Special Education

The University of British Columbia
Vancouver, Canada

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Abstract

The meaning and sense of self of primary caregivers caring for a family member with dementia was studied in this thesis. Four primary caregivers participated in a narrative research support group. Using a qualitative narrative methodology, based on White (1998) and Myerhoff's (1982) definitional ceremony, individual narratives and a collective narrative of the experiences of caregiving were constructed. Lieblich, Tuval-Mashiach, and Zilber's (1998) whole/content narrative method was used to analyze the individual narratives and collective group data. As was expected from a constructivist perspective, the caregivers made meaning of the changes in their lives on an ongoing basis, and their sense of self was shaped by this meaning. Participating in the research group also contributed to the caregiver's co-construction of meaning and identity in their caregiving. The collective narrative added a new layer to the research the experience of caregiving, was a rich source of learning from primary caregivers and contributed to the participants sense of community.
Table of Contents

Abstract ........................................................................................................................................ ii
Table of Contents .......................................................................................................................... iii
List of Tables ................................................................................................................................... vi
Acknowledgments ........................................................................................................................ vii

Chapter I: Overview and Introduction .......................................................................................... 1
  Research Goals ............................................................................................................................... 3
    The researcher's worldview. ........................................................................................................ 4
    The participants' narratives. ........................................................................................................ 5

Chapter II: Literature Review ......................................................................................................... 8
  A General Description of Caregiving and Its Outcomes ............................................................ 8
    Topics in caregiver research. ...................................................................................................... 8
    Meaning in caregiving. .............................................................................................................. 9
    Sense of self in caregiving. ........................................................................................................ 10
    Support groups. ......................................................................................................................... 12
    Summary: Communal knowing. ............................................................................................... 13
  Narrative Methodology, Its Assumptions, and Its Effects ........................................................... 15
    The purpose of the study. .......................................................................................................... 17
    The rationale for the study. ........................................................................................................ 18

Chapter III: Method ...................................................................................................................... 20
  The Collective Narrative Group .................................................................................................. 21
  The Participants ......................................................................................................................... 25
    Primary caregivers. .................................................................................................................... 25
    Researcher ................................................................................................................................ 27
  Data Collection and Analysis ...................................................................................................... 27
    Data collection. .......................................................................................................................... 28
    Data analysis. .............................................................................................................................. 28
      Researcher influence ............................................................................................................. 33
      Voice ..................................................................................................................................... 34
      Audience ............................................................................................................................... 35
      Creating a collective narrative .............................................................................................. 36
    Criteria for evaluation. ............................................................................................................. 36
    Ethical considerations. .............................................................................................................. 39

Chapter IV: Results ........................................................................................................................ 41
  Observations of the Group Process ............................................................................................ 41
  Interpretations of the Individual Stories .................................................................................... 46
    A Moment in Time. .................................................................................................................... 46
    An Unexpected Sadness. .......................................................................................................... 49
    The Two of Us. ......................................................................................................................... 50
    Caregiver at Heart. .................................................................................................................... 52
  Similarities and Differences of the Group Participants ............................................................. 53
    Differences between the participants. ...................................................................................... 53
<table>
<thead>
<tr>
<th>Theme One: Struggling with practical aspects of caregiving</th>
<th>58</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moment of diagnosis</td>
<td>58</td>
</tr>
<tr>
<td>Caregiving at home</td>
<td>60</td>
</tr>
<tr>
<td>Negotiating life with a care facility</td>
<td>62</td>
</tr>
<tr>
<td>Protection and respect</td>
<td>65</td>
</tr>
<tr>
<td>Theme Two: The caregiver’s life in community</td>
<td>67</td>
</tr>
<tr>
<td>Social support</td>
<td>68</td>
</tr>
<tr>
<td>Family dynamics</td>
<td>73</td>
</tr>
<tr>
<td>Putting the caregiver’s life on hold</td>
<td>77</td>
</tr>
<tr>
<td>Theme Three: Caregiver Health</td>
<td>80</td>
</tr>
<tr>
<td>The physical process of caregiving</td>
<td>81</td>
</tr>
<tr>
<td>The negative emotional experiences of caregiving</td>
<td>82</td>
</tr>
<tr>
<td>Theme Four: Shaping caregiving in the research group</td>
<td>90</td>
</tr>
<tr>
<td>The benefits of caregiving</td>
<td>90</td>
</tr>
<tr>
<td>Self care</td>
<td>91</td>
</tr>
<tr>
<td>Meaning in caregiving</td>
<td>94</td>
</tr>
<tr>
<td>Theme Five: The research experience</td>
<td>98</td>
</tr>
<tr>
<td>Writing the narratives</td>
<td>98</td>
</tr>
<tr>
<td>The support group experience</td>
<td>99</td>
</tr>
<tr>
<td>Reflections on the Research Process</td>
<td>100</td>
</tr>
<tr>
<td>Parallels in my caregiving experience</td>
<td>100</td>
</tr>
</tbody>
</table>

<p>| Chapter V: Discussion                                   | 102 |
| Comparing Research Connections                          | 102 |
| Physical and emotional strain                           | 102 |
| Stress and burden                                       | 104 |
| Benefits                                                | 105 |
| Social support                                          | 105 |
| Changing roles                                          | 106 |
| Putting life in limbo                                   | 107 |
| Social isolation                                        | 108 |
| Grief and loss                                          | 108 |
| New insights                                            | 109 |
| Meaning in Caregiving                                   | 109 |
| Sense of Self: Individual and collective identity       | 112 |
| Core or relational self                                 | 113 |
| Self care                                               | 114 |
| A Research and Therapy Method                           | 115 |
| The research group                                      | 116 |
| Narrative: Individual and collective                    | 116 |
| Collective narrative as definitional ceremony and reflexivity | 119 |
| Collective narrative as ritual                           | 121 |
| Successes and Limitations of the Study: Future implications for research | 122 |
| Conclusion                                              | 125 |</p>
<table>
<thead>
<tr>
<th>References</th>
<th>128</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendices</td>
<td>134</td>
</tr>
<tr>
<td>Appendix A: Consent Form for Participants</td>
<td>134</td>
</tr>
<tr>
<td>Appendix B: Poster to Advertise for Participants</td>
<td>136</td>
</tr>
<tr>
<td>Appendix C: Handouts for the Support Group</td>
<td>137</td>
</tr>
<tr>
<td>Appendix D: The Participant's Individual Narratives</td>
<td>151</td>
</tr>
<tr>
<td>Appendix E: The Collective Narrative of the Support Group</td>
<td>162</td>
</tr>
</tbody>
</table>
List of Tables

Table 1: Outline of the Group Sessions ............................................. 24
Table 2: Model of Narrative Analysis .................................................. 29
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Chapter One: Overview and Introduction

When you remember me, it means that you have carried something of who I am with you, that I have left some mark of who I am on who you are. It means that you can summon me back to your mind even though countless years and miles may stand between us. It means that if we meet again, you will know me. It means that even after I die, you can still see my face and hear my voice and speak to me in your heart. For as long as you remember me, I am never entirely lost. When I am feeling most ghost-like, it's your remembering me that helps remind me that I actually exist. When I'm feeling sad, it's my consolation. When I'm feeling happy, it's part of why I feel that way. If you forget me, one of the ways I remember who I am will be gone. If you forget me, part of who I am will be gone. (Buechner, 1992, p.14)

The story of this thesis began with the awareness of the cost of forgetting. In particular, it began with the cost of forgetting for caregivers of a family member with dementia. Family members with dementia are forgetting. They have been diagnosed with a degenerative condition that slowly causes the disintegration of the person they once were. Their caregivers become responsible for both their own and the afflicted family member's memories. Although holding memories may seem a static activity, the caregivers live with constant change. Over the years of the disease, caregivers go from being spouses, or children, who have an adult relationship with the afflicted person, to being the ones who take complete responsibility for their family member. This change in relationship, combined with social expectations, financial reality, and personal choices make the role of the caregiver an intense and challenging experience.

Dementia often begins by affecting the sufferers' memory for words and for the location of things. It progresses to disrupt short-term memory. With Alzheimer's disease in particular, people slowly move back through their lives as more memory disappears. They live further and further in the past, and live more and more in their own private reality. In all dementia, memory for daily activities is affected as well: how
to cook, how to dress, how to conduct tasks such as shopping and banking, how to participate in favorite hobbies, how to recognize grandchildren and say their names are a few of the daily routines that are disrupted. Eventually people with dementia forget how to sleep. They forget that they have asked the same question over and over again and received the same answer. They forget that they can trust the person caring for them. Finally the body forgets how to function. The people die. The forgetting ends.

Forgetting is not the lot of the caregivers. As the dementia progresses, the number of things to remember increases. The caregivers must compensate to provide what is being lost. Usually this brings profound changes in lifestyle. In this study the participant caregivers explore the costs and benefits of their experience by sharing their process of making meaning of this part of their life. They also told about their shifting sense of self or identity as caregivers for a family member with dementia. Their experiences are highlighted in story form throughout this work. Using the voice of another author, quotes from Frederick Buechner's *Listening to Your Life* (1992) were given to the caregivers in this research. They are interspersed throughout this thesis as pictures of the life awareness available through writing.

Through this research, I became a part of the web of remembering. My interest and motivations to do work in this area grew gradually. It stemmed from the honour I felt in hearing the lifestories of elderly people. Becoming aquainted with the lifetimes people have lived increased my sense of the richness of life and the expansiveness of time. It also brought me an awareness that caregivers are not given a strong voice in Canadian society.

Having a voice is part of both sharing the meaning of one's experience and presenting the identity of the person or group who is talking. It is part of the ongoing human process of living and becoming. This identity and personal meaning can change through the experiences of being a caregiver. From a communal point of view, identity is not created in isolation. It is a combination of the individual and the society. If this is so, then people who have common experiences, such as caring for a family member, may also create a caregiver cultural identity. Any similarities found among
primary caregivers with respect to meaning and sense of being may develop a communal identity. I was curious about this development. In addition I wanted to study the tension between individual growth and the demands of caregiving. I also intended to use the power of community for the benefit of the individuals in this study. For these reasons, I became part of the web of support for caregivers.

By creating a place where it was possible to listen to how caregivers story their lives, an opportunity was found to acknowledge and validate their personal being. Through this process of story-ing, it was possible to draw on the strengths of their personal growth and the community identity of the caregivers for the benefit of informal and formal caregivers alike. Listening to the stories in this study provided an opportunity to learn about meaning and communal identity. To remember using identity and meaning is to address the 'who I am' of Buechner's quote and is one possible step towards ameliorating the cost of forgetting.

Research Goals

This research project was unique in that it provided an opportunity for a group of primary caregivers to write and share their stories with the intent of creating a communal caregiving story. As mentioned above, the experience of caring for a family member with dementia has its own physical and psychological challenges. In recent years, research has extended to the investigation of the positive aspects of such caregiving. Research on positive experiences reflects the personal resources of caregivers. However, the caregiving experience needs to be explored further from the caregiver's point of view in order to create insightful and useful stories that will have an impact on support networks and understanding the experience of caregivers. Towards this purpose, I conducted this study using a collective narrative qualitative approach.

Many quantitative and qualitative\(^1\) research studies have been conducted on caregiving in the context of Alzheimer's Disease and dementia. Quantitative research

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\(^1\) Quantitative and qualitative research methods are two different ways of acquiring knowledge in research. Quantitative methods follow the rules of empirically based, Cartesian science. It looks for measurable truths using tests and hypotheses. Qualitative research is deductive in its approach to research findings.
in this field has provided us with important empirical evidence that caregiving is a task worthy of attention. It has also been important in guiding our program implementation for caregivers and their family members (Polkinghorne, 1991).

Rich qualitative research has added to the body of knowledge around dementia care by providing in-depth thematic descriptions of the caregiving experience. Most of the qualitative studies to date have been individual case studies, or studies of families' perceptions. The collective narrative (the creation of a communal story) is one form of qualitative research. It has not previously been used with caregivers of family members with dementia. This study adds to the growing body of rich, experience-based caregiving literature by using a writing research methods of individual and collective narratives to listen to the personal voices of the caregivers and to look for a collective (cultural) voice in the experience of this type of caregiving.

Narrative description of experiences gives the research field a direct account of what is important to caregivers. The people with the experience author the story. It also allows the participants of the study to share and examine their lives for the purposes of gaining insight, creating the ongoing sense of self, and making personal meaning of life. By creating a collective narrative, the meaning that caregivers give to their experience can be shared and reinforced in a communal context. This is best accomplished in a safe, comfortable support group setting.

The researcher's worldview.

In narrative and constructivist theory, each participant in the research, including the researcher, has a point of view which influences the meaning and interpretation of the research findings. Being explicit about these points of view was part of creating a responsible and useful research study. My role as a researcher was influenced by my personal philosophy of both life and of counselling. How does one live life? How does one do therapy? These two questions are irrevocably intertwined. I considered them

Qualitative research is a process-based method which stems from the assumption that human beings are in a constant journey of becoming. People create meaning for their lives and integrate their experiences based on this meaning. Qualitative research is inductive, epistemic, and hermeneutic in its approach. The important questions and insights emerge from the research as it happens. Many social science researchers see the importance of including both methods in the study of psychology, anthropology, social work, and other related disciplines.
during this research process. My personal philosophy is made up of the values and beliefs which impact my personal and professional life. They create my image, picture, or vision of how it all fits together. This is an ever-changing experience of how to negotiate living. This vision includes encouraging health, supporting abundant life, understanding and accepting the human condition, exploring experience, validating people, valuing voice and worldview, finding the explanatory or encompassing power of theory, encouraging hope, and balancing connection and separation.

In relation specifically to the role of caregiving I have several assumptions which impact this research. First, we have to care for ourselves as well as for others. No person is more or less important than another, and this influences how energy will be expended when caring. Second, community and interpersonal support are important parts of the process of living. We are validated by, and partially define ourselves by, our connection to those around us. Third, we are responsible for our reactions to situations and choices in life. This means it is important to be aware of why we make the decisions we do. These three assumptions all have a direct impact on how I view caregiving and how I facilitated the research for the participants in this thesis group. Ultimately, the goal for me is to live life abundantly. If this is my personal goal, then it also becomes my assumed goal for the people I see in my professional life. These biases will be highlighted in places where they influenced the research process throughout this thesis.

The participants' narratives.

It becomes clear that the process of writing is both personal and communal. Writing an individual story is personal in that it provides the author with time to reflect and make meaning of life. Writing is communal in that sharing the experience with others is potentially validating and can create interpersonal connections. Given these outcomes, both personal and communal experiences can be viewed as valuable steps in navigating the caregiving journey.

The research design used was able to encompass and validate whatever experiences the participants shared. It was a means of preventing my preconceptions from dictating the research. From the description above, it was clear that I have preconceived ideas of what the transition of caregiving can be like, however, my purpose in this study was to explore how the participants describe their own experiences. The study was an opportunity for participants to learn about self and transition from each other.

The use of a qualitative, narrative design was also central to the expected benefits of this project. First, it allowed the participants to express both a personal and a communal voice. Writing and sharing narratives is a process of development that encourages empowerment, reflection and the appraisal of beliefs. Second, creating a collective narrative tapped into the learning of a group experience. Sharing personal experiences in this way was helpful in building both community and support networks. Processes such as normalizing, instilling hope, sharing practical information, and decreasing feelings of isolation encouraged support. These networks are important to the caregiving journey.

This study contributes to the lives of families dealing with dementia by providing an innovative experience for caregivers to learn, find support, and heal themselves through a creative and meaning enhancing activity. This type of research provides resources to help people live in a dignified and fulfilling way. It asks them to be the creators and narrators of their lives.

For the purposes of this research, I was interested in using the creative format of a writing research group to explore the caregiver's sense of meaning and sense of self in the experience of caring for a family member with dementia. It was assumed this would not only provide one new, community-based voice of caregivers in the research, but it would be a healing experience for the caregivers as they make sense of their lives and move toward the future. The process of writing and sharing caregiver stories provided participants with a chance to reflect on their choices, perceive that caregiving is a transition experience, and reshape their sense of self. Utilizing a group writing format the research asks: "How does the process of caring for a family member
with dementia impact the caregiver's sense of personal meaning and sense of self?"
This question is mirrored in the following quote:

What I propose to do now is listen to my life as a whole, or at least to certain key moments of the first half of my life thus far, for whatever of meaning, ...there may be in it to hear. My assumption is that the story of any one of us is in some way the story of all of us.

For the reader, I suppose, it is like looking through someone else's photograph album. What holds you, if nothing else, is the possibility that somewhere among all those shots of people you never knew and places you never saw, you may come across something or someone you recognize. In fact - for more curious things have happened - even in a stranger's album, there is always the possibility that as the pages flip by, on one of them you may even catch a glimpse of yourself. Even if both of those fail, there is still a third possibility which is perhaps the happiest of them all, and that is that once I have put away my album for good, you may in the privacy of the heart take out the album of your own life and search it for the people and places you have loved and learned from yourself, and for those moments in the past - many of them half forgotten - through which you glimpsed, however dimly and fleetingly, the sacredness of your own journey. (Buechner, 1992, pp.10,11)

Listening to the life stories and experience of others was the method of creating connection and meaning making for the participants in this study. As is shown in the next chapter, it is the assumption that life stories have such outcomes which opens the possibility of creating a collective narrative for this caregiving group.
Chapter Two: Literature Review

A General Description of Caregiving and Its Outcomes

Research about informal caregivers of family members with dementia (often Alzheimer's disease) has been prolific since the mid 1980's. Although the family member with dementia is an important person when considering this subject, due to this study’s research emphasis on the caregiver’s self and finding meaning in caregiving, I will focus my literature review on the caregiver’s experience. This review describes general topics in the field of caregiver research, the importance of making personal meaning, some descriptions of how sense of self can be affected by caregiving, the effectiveness of caregiver support groups, and a description of narrative research methodology.

Topics in caregiver research.

The literature has focused primarily of the physical and emotional strain of the caregiving experience (Chenoweth & Spencer, 1986; Fisher & Lieberman, 1994; Lieberman, & Fisher, 1995; Mui & Marrow-Howell, 1993; Mullan, 1998; Schulz, O'Brian, Bookwala, & Fleissman, 1995). There is extensive research on the burden, and stress of caregiving using stress and coping models (Brathwaite, 1996; Dunkin, 1998). Other topics have included how caregivers handle different roles in their lives (Martire, Paris-Stephens & Atienza, 1997; Pavalko & Woodbury, 2000), depressive symptoms in caregivers (Li, Seltzer & Greenberg, 1997), social support (Abel, 1989), the difficulty of dealing with the ambiguous nature of Alzheimer’s disease (Garwick, Detzner, & Boss, 1994), and ethno-cultural influences on caregiving (Connell & Gibson, 1997; Cox & Monk, 1996). Another general topic of the research deals with personal and family traits such as the marital relationship (Lewis, 1998), adaptability (Majerovitz, 1995), spirituality (Chang, Noonan, & Tennstedt, 1998), mastery and self-esteem (Martire, Paris-Stephens, Franks, 1995; Skaff, Pearlin & Mullan, 1996). Gender differences in caregiving, and the experience of parent care have been examined by Merrill (1996) as well as by Sherrell & Newton (1996). Finally, the positive emotional rewards of caregiving, such as the increased emotional closeness
and long term sense of competency, are becoming more prevalent in the literature (Walker, Pratt, & Eddy, 1995). Overall, however, the caregiving experience is seen as a challenging life transition. "The family caregiver for an Alzheimer’s patient (or person with other dementia) is not simply adjusting to providing care, but also to the deterioration of a loved one, loss of social opportunities, severe financial burden, and a host of other problems" (Dillehay & Sandys, 1990, p.282).

**Meaning in caregiving.**

Understanding how caregivers make meaning of their experience has been an interesting focus of the literature which has particular relevance to this study. How the caregiving experience fits into a person’s world view directly impacts how they perceive the meaning of their life. In 1997, Noonan and Tennstedt conducted a quantitative study of how meaning in caregiving effected the caregiver’s sense of well-being. They found that caregivers who gave meaning to their work and personal relationship also had a higher sense of well being, although they warn that the direction of causality is not clear. What was clear is that the type of meaning a caregiver made was significant in lowering depressive symptoms and resulted in higher scores for self esteem. They did not find significant effects for meaning in connection with mastery, role captivity, or loss of self. In another study, Sheehan and Donorfio (1999) used grounded theory to examine how daughter caregivers and their mothers created meaning in their relationships. They found that caregiving changed the relationship by increasing acceptance, causing a redefinition of the relationship, and placing a stronger sense of priority on the importance of the mother - daughter interaction. The daughters expressed a theme of sacrifice which manifest itself by returning the caregiving time which their mothers had given to them. Perry and Olshansky (1996) found from studying how one family came to terms with Alzheimer’s disease that the family members went through a similar process to one another when creating meaning for the caregiving experience. These studies indicate that making meaning is a common experience, and that the type of meaning attributed to caregiving can change as the process progresses.
Sense of self in caregiving.

The literature describing sense of self and the research on how it relates to caregivers is complex and has reported mixed outcomes. Manheimer (1992) in his conceptual paper on the search for self, outlines the differences between the narrative self, the behavioural self, the post-modern self, and the phenomenological self. For the purposes of this study I will focus on the narrative and the post-modern definitions of self. The narrative self involves the interpretation of literary texts. These interpretations evoke a meaning of the word ‘self’, rather than attempting to explain it. Kaufman (1986) used this narrative approach in the study of sense of self among 60 older people. She described the sense of self observed in her interview study as the Ageless Self. The Ageless Self involved themes of continuity in self-perception which lead Kaufman to "equate self with identity" (Manheimer, 1992, p. 323). Self, in Kaufman’s study, is defined as the sum of the characteristics that make up an individual. These characteristics may change in detail or degree, but remain consistent at some level. It is how people perceive the characteristics as a whole which seems to be used by participants to attribute meaning to life experiences.

The post-modern view of self takes this emphasis on the attribution of meaning one step further. Manheimer (1992) states "the integrated self, the coherent self, is a culturally and ideologically induced invention." (p. 328). In the post-modern view, the self is a co-construction of the individual and those around them. If this is the case, then self perceptions can change and be influenced by both other people and outside experiences. A person is constantly in the process of becoming who they are by interacting with life, but they have a sense of personal characteristics over time called the self.

Troll and Skaff (1997) also found that a perceived continuity of self exists. This finding came from their phenomenological study of 150 people over 85 years of age. In their study, having a sense of continuity of self was related to positive affect (feeling good), and was not related to any current disruptive events in the subject’s lives. This would imply that people who feel their sense of self is a continuous entity over time are generally happy and this sense of self is not overly influenced by disruptive events.
such as caregiving. Not all caregivers are as old as the participants in the studies above, but these studies would suggest that a perception of continuity of self is important to health and meaning.

When looking particularly at the relationship between self perceptions and caregiving, the outcomes of the studies find both positive and negative effects. Skaff and Pearlin (1992) conducted structured interviews with 527 caregivers to determine what effect the caregiving role had on the caregiver's sense of self and the well-being of the caregiver. They found that loss of self, which was defined as a loss in identity due to becoming engulfed in the caregiving role, did occur. This was more common in spouses, female caregivers, and younger caregivers. Perceived loss of self was also related to greater social isolation, lower self-esteem, less sense of mastery over the experience, and an increase in depressive symptoms. Globerman (1994) had similar findings in a qualitative study of 6 families (2 at each stage of the beginning, moderate, and severe stages of Alzheimer's caregiving). Her findings described the restriction of family member roles and the ambiguity of the disease process as themes in the loss of self. In a more recent study, MacRae (1998) interviewed familial caregivers using a qualitative methodology. She found that caregiving involved intense emotional work for these caregivers. They attempted to manage their own feelings during the caregiving process and the results showed that failure in emotional management negatively effected the caregiver's sense of self.

In contrast to the above studies, Bar-David (1999) reported positive effects of the caregiving experience on the caregiver's sense of self. Through qualitative interviews she found that the caregivers in her study went through three phases of self development during the caregiving journey. This was described as developing a caring capacity for the care-recipient, followed by self-care in the caregiver, and leading to a caring capacity for others. The process was seen as expanding the caregiver's sense of self.

Pearlin (1992) describes the caregiving experience as a caregiving career. Caregiver's self concepts are in a state of flux due to the changing demands of the situation. In this view, the journey is divided into three stages: the Residential stage
Collective Narrative with Caregivers

when the family member lives at home, the Institutional stage where the family member is placed in long term care, and the Bereavement stage after the family member has died. I see the stages as having some over-lap, as Residential care often involves contact with institutions such as respite facilities, and Bereavement often begins as anticipatory grief before the family member has died. Pearlin's concept of the self in a state of flux fits well with the social constructionist view of the self as a process (see Core or relational self below). Regardless of the study under consideration, the literature seems to point to a change in the caregiver's perception of self through the caregiving process.

Support groups.

The use of support groups for caregivers is a well established practice. In 1996, Bourgeois and Schulz conducted a review of interventions for caregivers of relatives with dementia. They found that although there is a considerable amount of literature addressing this area, not many of the studies looked at the process of the interventions. They reviewed 19 studies which used support group interventions. Although some limitations such as sampling bias and lack of follow-up measures were cited in the studies, the outcomes were found to have neutral to positive effects. They included reports of participant satisfaction, increased understanding of the disease process, decreased feelings of isolation, increased assertiveness, and an improvement in problem solving abilities (Bourgeois & Schulz, 1996). One study reported that support groups are useful in the area of creating peer support, but are less useful in the area of alleviating the negative feelings of the caregivers, such as guilt and fear as it related to their relationship with the family member (Gonyea, 1989). In contrast, another older study by Lavorgna (1979) reported that members of the group met to share their emotions and experiences with each other, which helped them cope with their emotions. Gubrium (1988) took a look at levels of responsibility in caregiving. The support group is characterized as a place where members could "share their experiences and use what they had learned to assign meaning to their
own sense of responsibility, as well as (create) evaluations of other family members' responsibilities” (Gubrium, 1988, p. 199).

In his model of learning through group process, Yalom (1998) cites several therapeutic factors which can lead to the benefits experienced in a support group. His model lists the growth of hope, the normalization of experience, the gain of practical information, altruism, the development of skills for socializing, the opportunity to model behaviours, catharsis, the development of group cohesion, and the reduction of feelings of isolation as the possible benefits of group experience. A summary of how these effects emerged in this study can be found in the discussion chapter.

DeVries, Birrin, and Deutchman (1995) combine the support group process with narrative life review in their work with older adults (see also DeVries, & Deutchman, 1991). In their work they ask participants to write and read their personal stories in a group setting for the purpose of individual and group learning. Other outcomes of this process include gaining a global view of self, enhancing meaning of the life lived, awareness of cultural life experiences, and gaining some distance from experiences to increase personal control and insight.

Recent research has tried to address the limited use which some caregivers make of professional services in general, and support groups in particular. In her chapter “Constructing community care: (Re)storying support,” O'Connor studied 14 caregiving spouses of people with Alzheimer's disease and the underlying assumptions which influenced their use of available services. One of the themes was a feeling in caregivers that when using the services they experienced a decrease in sense of competency and were not seen as contributing equally to the support process (O'Connor, 1999). This would have implications when looking at the silencing of caregivers. If caregivers feel that they are not appreciated for what they can offer, then their competency and voice as a caregiver is negated.

**Summary: Communal Knowing.**

In a support group or a collective narrative, the commonalities of the participant’s journeys are highlighted. These commonalities are one type of common
knowledge or communal knowing which caregivers share due to their experiences of caregiving. Such commonalities expressed by the caregivers may include: feelings of isolation and a loss of support networks, feelings of anticipatory grief in the transition of losing a family member to dementia, feelings of powerlessness and failure in the face of the demands of caregiving, a silencing of personal needs and personal voice through caregiving. Some caregivers express the positive aspects of caregiving. Continuing the personal relationship in an altered form, learning about existential meaning and loss, and gaining personal strength from the experience are all seen as significant benefits in the caregiving experience. Both the positive and the negative experiences can effect the caregiver’s sense of self.

What contributes to the creation of these commonalities and these needs in the process of caregiving? Along with the lifestyle changes mentioned in Chapter One, there are other personal reactions and needs which are a caregiver reality. The reality of a degenerative disease is that the needs of the care recipient continue to increase and the caregiver can not reverse or halt the progress of the disease. This often leads to feelings of powerlessness and failure. Sometimes expectations dictate that the caregiver attempts to provide care beyond what is reasonable for one individual. The caregiver can sometimes neglect to practice self care. The needs of the caregiver are put on hold, which can mean a loss of a part of self. The caregiver has to silence personal needs to cope with the immediate situation. When personal needs are ignored, a part of the caregiver’s voice is silenced and this can be part of an alteration in the sense of self. Such expectations influence caregivers’ perceptions of self which in turn can change their attributions of physical and emotional health, success or failure.

The research group discussed some of these commonalities of caregiving. It gave participants the power within the research process to reveal their experience. They had the opportunity to begin looking at larger human questions, such as the existential meaning of caregiving, and they could ground themselves as active participants in their story.
Using the collective narrative group was a significant addition to the caregiver research. It recorded and co-created the personal and communal meaning making process of the caregivers. The meaning of their experience shaped their shifting sense of self. Both meaning and sense of self had an impact on creating a successful life transition. As is typical of the new edge of research, this study asked the question of caregiver meaning and self using a method which provided direct, rich and useful insight into the life experience of caregiving. This study is one example of the communal knowing of this group about caregiving.

**Narrative Methodology, Its Assumptions, and Its Effects**

The narrative approach is heavily influenced by the social constructivist philosophical perspective. It has moved away from the traditional positivistic concept that there is one objective truth to be uncovered. Instead it proposes that the meaning which people attribute to their experiences is a more significant indicator of their reality than objective measures (Arvay, Lecture, March 2000). Events are filtered through the context of personal meaning. Health professionals constantly come into contact with this filtered meaning when helping clients.

Mishler (1986) in his discussion of research interviews as a form of discourse described how traditional methodologies "disregard the respondent's social and personal context of meaning" (p. viii). He goes on to assert that narrative methodology is better suited than other methodologies to study the central questions in the social and behavioural sciences, namely,

1. how individuals perceive, organize, give meaning to and express their understandings of themselves, their experience, and their worlds. ...and
2. how their understandings are related to their social, cultural, and personal circumstances (Mishler, 1986, p. ix).

There are several assumptions which provide a basis for narrative analysis. The first is that when two people communicate, the conversation is jointly constructed. The second is that the resulting discussion can be interpreted using a theory of meaning. In other words, the people involved in a discussion are constantly involved
Collective Narrative with Caregivers

in making meaning through what they say. This is both an individual and a reciprocal process. The person talking in the discussion attributes a certain meaning to what is being said. The person listening also gives meaning to what is heard. The meanings are shaped by the experience and world view of the individuals involved. It is possible to interpret research discussions by understanding the meaning each person gives to the conversation. The third assumption is that the meanings given to an event or experience are grounded in a context. This context is often a story, "a sustained account" of a part of life (Mishler, 1986, p. 67), or an "internally consistent interpretation of life experiences" (Cohler, 1982, p. 207).

Gee (1985) agrees that there is a human tendency to story life. He writes: "Probably the primary way human beings make sense of their experience is by casting it in a narrative form" (p.11). This point of view is endorsed by a large body of literature including Lieblich, Tuval-Mashiach and Zilber (1998), Riessman (1993), Sarbin (1986), and White (1998).

Research is meant to go beyond the surface of a situation to allow a greater depth of understanding. Using a human being's ability and need to create a narrative of life, researchers have access to a way to gain understanding about the narrator's (or participant's) experience (Polkinghorne, 1988). This research understanding is rich in meaning and metaphor. It has the many layers of action, emotion, consequence, and world view which can be included by an author in a story. Not only does the author embed meaning in the narrative, but the reader brings personal meaning and interpretation to bare when looking at the narrative. This is why narrative research has been described as "the science of subjective experience" (Mishler, 1986, p. 96). It uses the subjective worlds of all the people involved to create research information. Similarly, Pinkola Estes (1995) describes the tradition in many cultures of learning through culturally subjective teaching stories. Her anthropological research is an example of how narrative has been used as an effective way to explore life, psychology, and learning.

Making a slight switch from a research focus to a therapeutic focus, it is evident that narrative is useful to personal change processes. For Spence (1982), who
approached therapy from a psychoanalytic tradition, the impact of narrative therapy lies in understanding the difference between narrative truth and historical truth. Narrative truth is the truth as described in the constructed story. Narrative truth is the meaning that the storyteller gives to life experiences. It is this truth, and not the simple facts (or historic truth) which is seen as important for therapeutic change. The coherent, integrated personal story produces sufficient meaning and insight for change to occur. Narrative psychologists take this a step further and describe the process of creating the story as the important part of creating the self in reality (Arvay, Lecture, March 2000).

If creating the narrative in therapy has the ability to encourage change, then participating in narrative research has benefit for the participants as well. Besides the teaching quality described above, it often engenders an interest in understanding experience, and provides a sense of empowerment to the participants. It requires participants to "find and speak in their own voice" (Mishler, 1986, p. 118). This shifts the power in the research situation from the researcher toward the participant, and may move the participant from just story-ing his or her life toward an action based on the insight gained from the process (Mishler, 1986).

Narrative research and therapy fit into the tradition of using the fine arts in therapy. Creative expression (such as writing a personal story) is described as a healing act by authors in this field (Gladding, 1992; Ledyard, 1999; Warren, 1993). Similarly, the existential school of psychotherapy has long acknowledged the benefit of creativity in health and wellness (May, 1975). The positive effects cited by these authors include the empowerment of personal expression, and the expansion of the available streams of knowledge (beyond cognitive to physical, emotional and tacit resources) which can be tapped by a person during a creative act.

The purpose of the study

Using the stories of the caregivers to create a collective narrative allows them to first tell their stories and thereby create themselves in the telling. Collective narratives
are based on the work by White (1998) and Myerhoff (1992). Through what Myerhoff calls a definitional ceremony, communities have an opportunity to become active participants in their own history and provide their own sharp, insistent definitions of themselves and explanations for their destiny, past and future. They are then knowing actors in the historical drama they script, rather than subjects in someone else's study. They 'make' themselves, ... an activity which is not inevitable or automatic but reserved for special people in special circumstances. (Myerhoff, 1982, p. 100)

She goes on to explain that "Definitional ceremonies deal with the problems of invisibility and marginality; they are strategies that provide opportunities for being seen and in one's own terms, garnering witnesses to one's worth, vitality, and being" (Myerhoff, 1986, p. 267). The aim of this study was to provide a space where the participants could create their story, be validated, and learn from the group experience. In particular, the issue of what it meant to be a caregiver of a family member with dementia, including the implications on personal identity, were addressed. It was anticipated that this information will be useful for caregivers, their families, and professional support workers alike. The research question is: "How does the process of caring for a family member with dementia impact the caregiver's sense of personal meaning and sense of self?"

The rationale for the study

Given the power of narrative research to make meaning of experience, and the rich events in the life transition of caring for a family member with dementia, this study added to the literature by providing a voice of communal knowledge about the caregiving experience. It added to our understanding of meaning and self in caregiving by using a collective narrative method in a group format. The caregivers in the group created a small community which co-created a narrative of the group's experience of caregiving. This study took narrative research from the individual level to the creation of a narrative at the cultural, community-based, collective level of
knowledge about caregiving. The participants co-created an identity in the collective narrative which defined who they were and what caregiving meant to them.

This is significant to counselling psychology, as creating a collective narrative is one method to tap into the reporting and construction of communal identity (Myerhoff, 1986). It becomes a culturally defined identity without excluding the individual participant's voices. People are validated and empowered at the individual and the community level. Constructivist theorists have discussed how identity and meaning are continually shaped by both the individual and the context of the culture (McNamee & Gergen, 1992). This study is one example of a narrative that includes communal knowledge and identity in the context of the caregiving culture. Creating a communal identity was an experience which shaped the continuing life of the research participants. Having a clear view of this small community identity may be helpful to enrich understanding of other similar caregiving communities.
Chapter Three: Method

In effect he (the artist) puts a frame around the moment, and what the frame does is enable us to see not just something about the moment but the moment itself. ... The frame sets it off from everything else that distracts us. It makes possible a second thought. That is the nature and purpose of frames. The frame does not change the moment, but it changes the way we perceive the moment. It makes us notice the moment, and that is what (the author) wants above all else. It is what literature in general wants above all else too. From the simplest lyric to the most complex novel ..., literature is asking us to pay attention. In sum, pay attention to the world and all that dwells therein and thereby pay attention to yourself and all that dwells therein. ... Literature, painting, music - the most basic lesson that all art teaches us is to stop, look, and listen to life on this planet, including our own lives, as a vastly richer, deeper, more mysterious business than most of the time it ever occurs to us to suspect as we bumble along from day to day on automatic pilot. (Buechner, 1992, p. 51)

The problem under consideration in this study is the personal impact of the life changing experience of caring for a family member with dementia. This type of caregiving is often a demanding life transition. The purpose of this study is to explore both how these caregivers express the meaning they may find in caregiving and how this experience may influence the caregiver's sense of self. From a narrative research perspective, the best source of information on the experience is the caregivers themselves. A qualitative methodology incorporates a chance for personal reflection and communal learning. It assumes that exploring the relationships and stories which emerge from this research can be beneficial to understanding the caregiving experience. The process of interacting was an opportunity for participants to notice the moment in which they were living and to define themselves through their story in the ongoing action of becoming.
Because caregiving is often a long and intense process, it is important to provide support to caregivers. This study used storytelling to give caregivers a personal voice. Thus it provided a space for the empowerment of the caregivers. It gave them a supportive environment in the group setting, which allowed caregivers to learn from each other. Through sharing discussion and reflexive thought about their narratives, caregivers allowed for the necessity of self care, acknowledged the personal limits caregivers can reach as human beings, and clearly illuminated the benefits of the caregiving experience.

The Collective Narrative Group
In the long run stories all overlap and mingle like searchlights in the dark. The stories (you tell) are part of the story (you are), and the other way around. ... My story and your story are all part of each other too if only because (we have spent time together) and seen each others faces so that we are at least a footnote at the bottom of each other’s stories.
In other words all our stories are in the end one story, one vast story about being human, being together, being here. Does the story point beyond itself? Does it mean something? What is the truth of this interminable, sprawling story we all of us are? Or is it as absurd to ask about the truth of it as it is to ask about the truth of the wind howling through the crack under a door? (Buechner, 1992, p.305)

The participant’s narratives intermingled and overlapped with the end result of the creation of a collective narrative of caregiving from the research group. The group took place using a five session group format. Based on recommendations from focus group research, the target size for the group was 4 caregivers with one facilitator (Morgan, 1989). For the purposes of anonymity the caregivers are referred to by initial only throughout the thesis. After negotiating with several community agencies, the group found a home at the Vancouver General Hospital Geriatric Psychiatry Outreach Centre.
The group met for five weeks on Wednesday afternoons, between 1 and 3pm. The afternoon time was decided in consultation with the supervising liaison at the Centre. Mid afternoon was seen as a good time, as it was easiest for older people to get to the meeting. It was the height of the energy of the day. It also allowed the use of the liaison’s office, which was only available during office hours. The office was a comfortable room. It was large enough to seat five people in a circle and was regaled with black and white pictures, plants and a Persian carpet.

Participants went through an introductory screening session to determine their suitability for participation. The suitability criteria were: experience as an informal primary caregiver in the later phases of caregiving, interest in taking part in the group, and willingness to give informed consent to participating in the research (see Appendix A).

The format of the group is outlined in Table 1 (p. 24). The group sessions lead the participants through a process of forming the group, writing and sharing their personal stories, creating a collective narrative, and leaving the group experience. The sessions were audiotaped, and brief research notes were made during the sessions. These were transcribed and used to create the member check outlines for the group. The following is a brief description of the activities for each session.

In the first session, introductions and information provided a basis for forming a working group. This included content about the process and purpose of the study as well as information about what is presently known about the experience of caregiving. Each week an outline of the session was handed out for the meeting. The emerging research questions and themes from the previous session were included in the weekly outlines. I handed out an outline for session one (see Appendix C). Also as part of the first week, each participant was given a notebook and pen, and a few pages of quotes from Frederick Buechner’s book *Listening to Your Life* as inspiration for writing the caregiver stories (see Appendix C).

In the second session participants were asked to share their experiences and begin to write their personal caregiving narrative: (1) A participant check-in was followed with a summary of the information from the first session (see Appendix C).
(2) Time to begin composing their personal narratives was included in the session. Guiding questions which can be found in the handout Writing Your Story of the Experience of Caregiving (see Appendix C) were given out as a way to begin writing. Twenty minutes in the session were devoted to the exercise. (3) Participants were informed again that the narratives would be shared in the group the following weeks.

In the third session the purpose was to listen to and learn from participants' narratives: (1) A participant check-in was followed with a summary of the information from the second session (see Appendix C). (2) Guidelines for respectful feedback were discussed (see Appendix C). (3) Two members had the opportunity to read their narrative to the group. F started and V read after her. (4) A group debriefing of the experience of reading the narratives in the group finished the session. (5) The two narratives that had been read were collected at the end of this session, so that I could analyze them for general themes and common experiences.

Between session three and four, on March 8, 2001, I met with R at her home to transcribe her story of being a caregiver. She was not comfortable with her English language writing skills. She talked and I wrote. We edited the story until she was satisfied. After we were finished she mentioned a few things that were significant to the questions of the study. These included changes in her social networks, issues of the social acceptance of grief and changes in her personal expectations of being a caregiver.

In the fourth session the process of reading individual narratives was continued, followed by time for discussion afterward. (1) A participant check-in was followed by a summary of the information from the third session (see Appendix C). (2) The two remaining individual narratives were read in the group. L read her narrative first. R read second and completed the reading of individual narratives in the research process. (3) The group finished with free discussion of related topics.

The fifth and final session was designed as an opportunity to work together to complete a collective narrative of the caregiving and research group experiences. The participants spent some time on debriefing and bringing some closure to the support
Table 1: Outline of the Group Sessions

<table>
<thead>
<tr>
<th>Session Number</th>
<th>Title of Session</th>
<th>Objectives</th>
</tr>
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<tbody>
<tr>
<td>Session One:</td>
<td>Meeting Each Other</td>
<td>Describing: the process of the sessions, the content of the sessions, how the research literature has outlined the caregiving experience and the purpose of the study. Developing: group safety and cohesion</td>
</tr>
<tr>
<td>Session Two</td>
<td>Writing Your Personal Story</td>
<td>To ask participants to describe their caregiving experiences by writing it in story form.</td>
</tr>
<tr>
<td>Session Three</td>
<td>Sharing Your Story with the Group</td>
<td>To learn from and listen to the personal stories read in the group.</td>
</tr>
<tr>
<td>Session Four</td>
<td>see session 3</td>
<td>see session 3</td>
</tr>
<tr>
<td>Session Five</td>
<td>1. Creating a Collective Narrative</td>
<td>1. To use the principles of narrative therapy to describe the group's experience of caregiving. 2. Group reflection and closure on their experiences in the study.</td>
</tr>
</tbody>
</table>
group meetings: (1) A participant check-in was followed with a summary of the information from the fourth session (see Appendix C). (2) The better part of the session was spent looking at the initial outline of a collective story which I brought to the meeting. We discussed similarities and differences between participant's caregiving experiences. There was a discussion regarding their theories of what happened during their process of caregiving. (3) The session finished with several closure activities. These included discussions of the writing experience and feedback for me about the group process (see Appendix C). I distributed the handout References for Personal Counselling (see Appendix C), and discussed the possibility of getting further help if the group experience brought up emotional issues that might need exploration with a counsellor. I arranged with each group member to meet individually in six weeks time to deliver a booklet of the compiled narratives of the group. This booklet consisted of each participant's individual narrative and the collective narrative of the group.

About six weeks after the group ended I visited each participant as a follow-up to the group. I showed each person the changes I had made to the story. These changes were a result of consulting with F about the communal story at our final interview, as she was not part of the narrative process in the last session. I asked each person how she had been doing in general since the group experience, and if there was anything to discuss as a result of the group. I also gave them a bound copy of their stories which we had read and created in the research group. The participants wanted to have all five of the stories (one from each participant and the collective story) as a keepsake from the experience. They each gave their verbal permission to give their printed story to the others. Thus, the end results of this study are the personal stories of each individual participant and a collective story which describes the experience of the caregivers as a group.

The Participants

Primary caregivers.

The participants I found to take part in the support group and the research had
provided care at home for a family member with dementia. They were in the later stages of caregiving; either providing care for a family member in a medical institution or finding closure after the family member had died. The reasons for these criteria are mentioned in the ethics section following.

I recruited participants through word of mouth, referral from Vancouver General Hospital Geriatric Outreach Services, advertising at community agencies (such as the Alzheimer Society of BC), and through posters in public areas. Initial contact was made with the participants through posters (see Appendix B). Fifty posters were sent to day centres for older people, long term care facilities, and hospitals in the Vancouver area. Several participants came through referrals from the directors at these sights, who attained permission from the people for me to call them directly to set up an interview. Initially, I visited with the participants in their homes. During these interviews, I further described the group as “A support research group using caregiver stories as its main form of interaction and information gathering,” and screened the people as primary caregivers of a family member with dementia who were in Pearlin’s (1992) last two phases of caregiving (Institutional care or Bereavement). The four participants then read and signed a consent form and we set the time to meet for the first group.

When interviewing participants, it became clear, that the time constraints of the group had an effect on who could take part as a research participant. The research participants were unemployed elderly individuals, with the exception of F who was in her fifties and was available because she had seasonal employment. Several other people could not participate due to work responsibilities.

The participants ranged in age from fifty to over eighty. Three of the four were wives of a man with dementia and one was an adult daughter of a mother with dementia. The duration of care ranged from three to seven years.

Participants choose to take part in the study because of a personal interest, and self-selected once they were given general information concerning the process. This lead to motivated participants who, although initially slightly intimidated by writing their narratives; were willing to articulate their experiences and participate in group
sessions. As anticipated, the participants took an active part in defining and describing their personal caregiving experiences, and created a collective story of the caregiving processes. The participants were considered to be co-researchers in the process of this study. Their perceptions and questions influenced the direction of the research. As I have never been a primary caregiver for a person with dementia (although I have worked in an adult day program and lead caregiver support groups), I considered the participants to be the experts on the caregiving process. My contribution was to facilitate the research and group processes.

Researcher.

My main role was to witness the participants' experiences and to listen to their personal points of view. This was accomplished through the facilitation of the support group process, and the validation of the participants. As mentioned above, data collection and analysis took into account the researcher as a participant in shaping the research results. My role was to provide a safe setting for the participants to create and share their experiences, to make use of the transcripts and my training to summarize their experiences, and to use this summary as a basis for the participants to create their collective narrative.

Data Collection and Analysis

If Literature is a metaphor for the writer's experience, a mirror in which that experience is at least partially reflected, it is at the same time a mirror in which the reader can also see his or her experience reflected in a new and potentially transforming way. ... Words written fifty years ago, a hundred years ago, a thousand years ago, can have as much power today as ever they had it then to come alive for us and in us and to make us more alive within ourselves. That, I suppose, is the final mystery as well as the final power of words: that not even across great distances of time and space do they ever lose their capacity for becoming incarnate. (Buechner, 1992, p. 170)
The data collection and analysis in this study focuses on the words of the caregivers. It is the caregivers' voices which come alive through each reading and interpretation. Their words are the reality of their experience. The narratives are the data to be explored for the meaning and mystery of how the caregiver's words make their experience incarnate.

The resources required for this research study included a site for the project (Vancouver General Hospital Geriatric Psychiatry Outreach Services), a multi-directional mic and audio recording device to record each session, a computer with a word processing program for transcription purposes, the handouts included in the appendixes of this proposal, and booklets for the initial and final narratives.

Data collection.

As mentioned in the “Purpose of the Study” section above, data collection followed the methods outlined by White (1998). The participants wrote their personal narratives of caregiving, participated in the discussions of the research support group, shared their individual narratives with the group, and created a collective narrative of the research and caregiving experience. Data sources for the study included audiotapes of the sessions, my write ups of each session, the written stories of the participants, my journal of the research journey, and the collective narrative. Each taped session was transcribed and analyzed looking for elements of a productive group process and themes in the caregivers’ experiences. This information was summarized for the group at the beginning of each session to keep participants as much involved in the research process as possible. The narratives of the participants themselves were the primary source of data. The collective narrative from the fifth session and the participant’s responses to this narrative were also important sources of data.

Data analysis.

The narrative analysis which was used in this study is based on the method developed by Lieblich, Tuval-Mashiach and Zilber (1998). Data analysis was
inductive and included thematic analysis of the participants' narratives, the researcher's exploration of common experiences and the participants' creation of a common narrative. The model used depicts narrative research as falling into four categories. These categories become the following four quadrants of research analysis.

Table 2: Lieblich, Tuval-Mashiach, & Zilber's Quadrants of Narrative Analysis (1998)

<table>
<thead>
<tr>
<th>Whole</th>
<th>Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category</td>
<td>Content</td>
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</table>

This Study

Any type of narrative research analysis will fall into one of the quadrants. The boundaries of the types of analysis (quadrants) are two dichotomous continua. The first continuum has a holistic data analysis method at one end of the line and a categorical data analysis method at the other. The holistic method looks at a story as a complete entity, whereas the categorical method divides the story into independent sections. The second continuum uses a content method on one extreme of the line and a form method at the other. The content method involves the reading and analysis of the story to draw themes from that story after it has been reported to the researcher. One example of this is the social support the author received in the story. Such a theme would emerge if the author mentioned social support as having an important (be it positive or negative) impact in the telling of the story. Once this impact
is notes, the researcher would read the story for the particular way the theme of social support shaped the story. The form method follows one idea through the story and graphs its course in a narrative. For example, one story can be read for the amount of personal contact the author had with another character. This level of contact can be graphed as part of the form of the story (Lieblich, Tuval-Mashiach and Zilber, 1998).

The holistic/content method was used for the analysis of the data from this study. Using this method I looked at the narratives as complete in and of themselves. The various experiences cannot be separated from each other and have an impact on the narrative as a whole. The experience of caring for a family member at home, for example, impacts on how the caregiver views the humanity of their family member or how she approaches moving the family member into long term care. The data collected was also analyzed on an ongoing basis for emerging themes in the group which were incorporated into the collective narrative.

Analysis of the data was ongoing throughout the research group process. As mentioned above, it included the transcriptions of the five group sessions, my personal research journal, the transcripts of the participants’ personal narratives, my outline of the collective narrative, and the group’s collective narrative. Themes emerged both from the narratives read in the group, and from the content of the participants’ discussions during the sessions. Each group session was written onto computer disk in as much detail as possible. I reviewed the transcriptions between sessions to summarize questions and themes. These summaries were brought to the group for feedback and member checks of the ideas. The summaries had an ongoing impact on the direction of the research group. They were outlines of what the participants contributed as well as my questions and impressions. All this highlighted information was fodder in the discussion mill each week.

After the support group was finished and all the data had been collected, I read through each summarized handout, volumes of my journal, and transcription of the sessions. During this reading, I looked at each section (sometimes several paragraphs) for the content of what was being said by the participants. I asked myself questions such as: What was the speaker discussing? Why was it important to the
person speaking? Have I seen anything like this in the other data collected? When I had determined the content and gist of the section of data, I typed it into the computer under a suitable heading. As this process progressed, segments of the data began to fit together. These were instances when the different data collection sources triangled with each other to create an idea or experience that was pervasive enough in the narratives to become a theme. A theme was a caregiver's experience which reoccurred several times in the narratives, or the discussion, and had the power to describe or explain significant parts of the individual and group caregiving experience. A theme had meaning to the researchers and was part of how the caregivers defined themselves in the caregiving experience. For example, the theme of The caregiver's life in community includes a major category called Putting the caregiver's personal life on hold. This category emerged from the data in session 1, session 2, a private interview on May 1, and two of the individual narratives. To add another layer to the analysis, the session discussions were influenced by the session summaries which I compiled from both my journal notes and the transcripts of the sessions.

After the themes and categories had emerged, I looked at each of them in relation to the individual participants. Did each participant address the idea at hand at some point in the process? In most cases all the participants made a comment on the themes and categories presented. This was part of the criteria I used in deciding to include the theme in the results.

The next step was to take the themes and write the collective narrative. I composed the first draft of the narrative without following the printed outlines of the themes. I wrote it from my memories of the group and research experience. I chose to do this as a way to allow my creative process to influence the narrative. I felt this would mean some of the phrases and sentiments are more natural due to this holistic approach. Then I checked the collective narrative to see if all the themes and some of the categories were represented in the collective narrative. Themes I felt had been underrepresented were then added to the draft of the narrative. It was this draft that was shown to the participants at the last meeting. This was how I analyzed the themes for the collective narrative.
I used a similar method when analyzing the process and development of the group. My journal entries and knowledge of group process informed the analysis here more than for the emergent group themes. In contrast, the comments of the participants in their narratives and the group discussion had a heavier weight in the group themes, because I wanted the themes to be more from the participants than from me. I felt this was important to the rigor of the study. For the description of the group process, however, I looked at the data sources in relation to theoretical models. Both Yalom's (1998) group outcomes and Weber's (1982) stages of group development were used to analyze the results of the group process.

Another level of analysis was the interpretation of the individual narratives of the participants. These narratives are a very significant source of data. They are the direct stories of caregiving. These were written and shared in the group, and were transcribed to disk (using appropriate coding to ensure confidentiality). I read them for themes and content (similarities and differences) between narratives. Following the development of the group themes and the analysis of the group process, I read the individual narratives for their themes and personal experience. I used my reading of the narrative and my experience of the individual person in the research group to pick out ideas that had particular importance to each participant. V, for example, put a strong emphasis on the impact of the loss of emotional connection she had experienced as a result of her husband's disease. This was a theme which coloured her narrative as a whole. It was valuable to analyze each narrative separately to keep the individual voices of the participants in the analysis. It also was one way to track how the feelings and ideas in the collective narrative took shape from the individual participants. For example, there is emotional strain for the caregivers in all four of the individual narratives. It also appears as a significant transition in the collective narrative.

My research journal provided a chronicle of my research process. I wrote in it almost daily as thoughts, information and impressions surfaced. For example, on March 19, 2001 I have an entry in the journal which clarifies my research relationship to the participants as it impacted creating the emerging research questions. The
journal was the place where I worked through my personal assumptions of caregiving. Making this apparent was important to the verisimilitude of the research findings. It was used to explain the development of themes and results in the study. As my journal was my paper brain, it influenced the collective story outline and session content. It focused my attention on specific areas during the research process. These areas included family dynamics, social support, and grief. Having noted them in the journal, and in the summaries of the research sessions, they were then included in the handout for session four (see Appendix C).

In summary, the data analysis resulted in themes which emerged from the session summaries, my journal, and primarily from the individual stories. These themes and related categories were the basis for my interpretation of the caregiving experience when I drafted the first outline of the group's collective narrative. I did this as a precursor to asking the group to write a collective narrative. It gave the participants a structure to build from or to change. My collective narrative outline was presented to the group in session five. I used it as a beginning point for the group to write a collective narrative. In the collective narrative, I encouraged the participants to connect the themes from the sessions, the individual stories, the outline, and possible influences of the culture we live in. These cultural influences may be either from the general culture or the culture specific to the group. The results of the cultural analysis and the research method are reflected in the findings of the research group process. I also analyzed the individual narratives as data for the caregiving experience, and as the unique voices of the participants in the study. After creating the collective narrative we reflected on the process of conducting the group. At this point I paid particular attention to moments where reflection on the topics of sense of self or sense of meaning in caregiving occurred for the participants. The results of the narratives are the transcripts of the participants' individual stories and the collective narrative which are included in their entirety in appendices D and E of this thesis (p.p. 161 & 172). The results for the ideas of meaning and sense of self are discussed in Chapter Five.

**Researcher influence:** I was aware of the interaction between the researcher
and the participants as being part of a group process, and how this interaction shapes the outcomes. As part of the group process I included a discussion on the use of narratives, how they provide a unique voice for caregivers in research literature and how they may be beneficial to finding meaning in the caregiving experience (session one). I assume this education of the participants about the research process changed, or at least influenced, the information that the participants included in the narratives. Ethically, providing this level of information is important in that it increases the possibility for participants to be equal research partners. My participation in the group made me a research tool, as I participated in discussions and interpreted the information given. In an effort to create a transparent description of the research process and the eventual results, I kept a journal of my research experience to be included in the analysis. This can be seen in the sections "Observations on the group process" where I discussed the useful aspects of teaching between group members in the research process. Another example is in the "Reflections on the research process" section where quotes from my journal express some of my personal learning during the study.

Voice: When writing, I wrote mostly in the first person voice. I used my perceptions and experiences to interpret the group's stories. In this sense I assumed that I have the ability to summarize the group experience and that my perceptions of the participant's interactions added to the knowledge of the group. The participants wrote in their personal voices and were thereby represented in the research process. By creating a communal narrative I attempted to move beyond simply speaking for the participants as in traditional research, but to allow the knowledge and experience of the group to speak for itself. In this way the thesis will present several voices: mine as the researcher, the participants through their individual narratives, and the group voice through the collective narrative.

When I wrote the collective narrative I tried to synthesize the stories read in the group, and the discussions we had. I have conscientiously tried only to included information and feelings that came from those two sources. I used summaries and quotes from the audiotapes of the research group as my source of data. In many
cases I could hear which group member had said a sentence as I typed it into the narrative. During the last session the group members took my outline and made the changes they wanted to make. Through the feedback process it became the group’s narrative. It is also an important way to ensure the authority and authenticity of the story. At some level, it remains, however, my distillation of the experience.

To tell the story in the past tense was necessary to encompass the complete breadth of the caregiving experience (beginning to end). The drawback of this voice is that it is less immediate and experiential for the reader. This may decrease the impact of reading it. A second and more influential choice was to tell the collective story in the personal voice of a spouse. I chose the spouse’s voice initially, as a jumping off point for the group process in the last session. Three of the four participants were spouses and the fourth participant has described herself that way in the group. I anticipated that we might decide to change the voice in the session. Another option was that of a generic caregiver, which in my opinion would have lost too much of the flavour of the present group. The specific relationship was a significant enough aspect not to be discarded. A third option would have been to write it from the plural ‘we’ voice. (e.g., We were devastated when our family member was first moved into a care facility.) This, however, begins to take on the tone of a science fiction movie. In my opinion, in the latter case the collective voice does dissolve the individual. During the session it seemed natural to keep the spouse’s voice as the only group members present were spouses.

Audience: The audience for whom the study is written will vary as well. At times I was the audience, in a personal attempt to learn and work through the process. My academic community is the final audience when the study is presented or published. The participants in the group are also a primary audience. They spoke to each other when sharing their narratives. Each participant spoke to herself individually while writing them. It is my hope that the narratives we created will be heard by others interested in the area of caregiver research and support.

When thinking about this, the necessity of appropriate confidentiality for the participants must be weighted heavily against the possible knowledge people may gain
from hearing about the experience. Ultimately, the main audience is the participants themselves. They wrote, and their participatory knowledge and interpretations emerge from their narratives.

Creating the collective narrative: The collective narrative was created using the following form of analysis. I used the tapes, other interviews (such as the visits to R and F’s houses), and the analyzed stories to create the themes found in the results section. These themes were used as a beginning structure for my outline of the collective narrative. The collective narrative was taken to the group on the last session for further development by the group members.

Several questions were used to guide the development of the collective story. These were: How were your experiences similar? What did they have in common? How were your experiences different? How does the process of caregiving create meaning for you? What is your sense of self or identity as a caregiver? What is your theory about what is going on?

The writing of the collective story was a four part process. It involved the participation of all group members for the first four sessions of the group. The second part was my initial outline of the collective story. This was my compilation created through listening in the group, and looking at the themes from the sessions, and asking the basic questions in the last paragraph. Although this story was based on the data collected in the sessions, it was inevitably presented through my filters. The third step was taking this outline story to the fifth session as a stepping stone for the participants to work with. During this step participants had the chance to change the story through feedback, which again made it less my story of the group and more the collective story. The participants were asked the same three questions as I asked myself in the second step. The fourth and final step was the finished story of the group.

Criteria for evaluation.

Evaluation of the results was ongoing throughout the research project. It was in writing and working with the group that an interpretive description of the caregiver’s experience emerged. The authority of the research results came from the direct
quality which resulted from the participants writing their narratives on paper and
telling them in the group. The authority of the findings were confirmed when the
summarized themes were accepted by the group. The participants felt resonance for
the collective narrative which was one indication of the effectiveness of the process.
Simply spending time with the participants and the research process also added to the
authority of the findings. We were working together, and working with the information
gained from the group process, to create a group experience and the existing results.

The rigor of the project included the clarity of communication around the group
process, my journal entries concerning the research process, and the narratives
shared in the group. These were some of the methods I used to trace the evolution of
the interpretations written in the study. One of the criteria was the extent to which the
stories and the group experience describes the relationships of these caregivers; both
as connected to and independent of the group. The richness of the expressions of
the relationships lead to a rich storytelling experience. This enhanced the potential for
personal and group understanding of the emerging self in the caregiving process.

An awareness of the possible influence of culture was also an important
criterion for evaluating meaning and self in the study. Society at large has
expectations which often influence how people act. The group itself created a
transient culture that also shaped interpersonal communication and the study results.
Thus, awareness of the impact of culture was part of describing the caregiver
experience and the verisimilitude of the research.

Following Lieblich, Tuval-Mashiach, and Zilber's model (1998) the analysis
resulted in themes gleaned from the research group. I also used an intersubjective
approach to the data; which included my subjective listening and interpretation of the
participants stories. I think this was particularly the case when analyzing F's story with
the strong influence of conflicted family dynamics on her caregiving relationship.
Shared reflexivity (see narrative and reflexivity section) and open subjectivity of my
research experience in the narrative and group process were two approaches to
providing a fair and critical presentation of the findings.
Lieblich, Tuval-Mashiach, and Zilber (1998) suggest four possible criteria for testing qualitative research. Although these are proposed for use with case studies, they are the criteria I also attempted to follow in my research. The following is a brief description of each:

1. **Width**: The comprehensiveness of evidence. This dimension refers to the quality of the interview and the observations as well as to the proposed interpretation or analysis. Numerous quotations in reporting narrative studies, as well as suggestions of alternative explanations, should be provided for the reader's judgment of the evidence and its interpretation.

2. **Coherence**: The way different parts of the interpretation create a complete and meaningful picture. Coherence can be evaluated both internally, in terms of how the parts fit together, and externally, namely, against existing theories and previous research.

3. **Insightfulness**: The sense of innovation or originality in the presentation of the story and its analysis. Close to this criterion is the question of whether reading the analysis of the life story of an "other" has resulted in greater comprehension and insight regarding the reader's own life.

4. **Parsimony**: The ability to provide an analysis based on a small number of concepts, and elegance or aesthetic appeal. (Which relate to the literary merits of written or oral presentation of the story and its analysis). (Lieblich, Tuval-Mashiach, and Zilber, 1998, p. 173)

Width was achieved both in the collection and the analysis of the data. I ensured that I had five sources for data collection (individual and collection narrative, the research group transcripts, my journals, and the session summaries for member checks) to add to the breadth of the information in the study. These sources were analyzed with the intention to provide interpretations with verisimilitude. There were numerous possibilities to be considered when presenting interpretations. Using the theme of family dynamics as an example, I interpreted F's family dynamics using the
analogy of unmet needs. I chose to go with the interpretation that had the most support for me in the data. The findings I have presented are open to other interpretation, which are also written in the findings.

I wrote for coherence in all the stages of the study. The collective narrative was one example of seeking coherence of the story of caregiving at a communal level. The comparisons between the literature review and this study's findings in the discussion section were explicitly written to place this study in the context of caregiving research.

The third criteria was insightfulness. By the reports of the research participants themselves, they gained new understanding of their individual and collective experiences. I personally felt I learned many new and rich things through the research process. The findings themselves are more a reaffirmation of previous research than an uncovering of major new themes in caregiving. Where the study does break interesting new ground is in the use of a collective narrative method with caregivers in this situation. The study provides an example of how meaning making through communal knowledge can be effective, to the research field as a whole, and particularly to the participants of the study.

Finally, I aimed for parsimony in the writing of this study. I sacrificed some of the elegance of the findings by including many direct quotes from the participants. I chose to do this for the sake of transparent triangulation of the research data. Of the four criteria, this was one not as successfully achieved as the other three. The exception to this is letting the compilation of narratives speak for themselves.

Ethical considerations.

Setting the criteria for selecting the participants was significant in ensuring their emotional safety. Caregivers are often perceived as a vulnerable group -- people who are dealing with a myriad of changing physical and psychological circumstances. It is for this reason that I proposed to work with primary caregivers who are in the later phases of caregiving [Pearlin's (1992) Institutional or Bereavement phases]. The day to day situation for these caregivers is often no longer as stressful as when the family member with dementia lived at home. I hoped this would mean that participants would
be in a psychological space to be able to make sense of their caregiving experience as a part of their lives. The one possible exception to this caveat was L. She was experiencing extreme amounts of stress during the research process as a result of her husbands recent move to a care facility and her separation from him. Creating safety in the experience is essential to any group, so I maintained an aware and careful approach to working with L in the group. She indicated that she found the group experience beneficial.

Discussion of life stories can brought up regrets about past experiences which needed to be addressed in the group, and may lead the participant to seek further help outside of the study. A list of counselling resources was made available to the participants should they feel the need for more help after the study (see Appendix C), and I visited the participants six weeks after the completion of the group to follow up informally on the group experience.
Chapter Four: Results

Throughout the weeks of the group it was important to revisit the questions “What am I as a researcher trying to do?” And “Why am I doing it?” (Journal, March 1/01). The answers to these questions can be unearthed in the results which are found in this chapter. Primarily, the research results are actually the narratives of the participants in Appendix E and F. They are the written experiences of caregivers who have a family member with dementia. To answer the above questions: I as a researcher was trying to illuminate the experience of caregiving for the benefit of the participants and the research field in general. The following chapter takes the primary results of the narratives and expands these using the experience of the support group to give a rich description of the experience of caregiving.

Observations of the Group Process

During the study, the research group had progressive goals which built up the group process. The first two weeks of the group were about sharing and building trust, safety, respect and inclusion. The third and fourth weeks were about reading the participant’s stories in the group (See Appendix E). The fifth and final week was reviewing the group process, bringing closure and developing the collective story. The latter looked at where the caregivers came together, where their experiences were separate, and how this impacted the group as a whole. The collective story can be found in Appendix F.

It became clear after the first week that the schedule needed to be changed from the one originally proposed. Originally, sharing the individual narratives would have been in session two and three, leaving the collective narrative for session four. This would have exclusively allowed session five for closure and wrap up. As it was, the group needed two weeks to really form itself. I moved the beginning of the individual story telling from week two to week three. This allowed the group to become more comfortable with each other and have more time to write before they spoke. It meant in the end that there was only one week (session 5) to create the collective story in the group. In future groups, I would expand the support group up to six weeks,
so that there would be two weeks for introductions and beginning to write, two weeks for reading the stories in the group, and two weeks to create the collective narrative and bring closure to the group. This pacing seems more realistic and natural. As it was there was some pressure to complete the group tasks.

There were difficulties with physical participation in the group. I assume the group process was effected by the fact that on several occasions group participants were absent from the sessions. During session five, V said “It’s so hard to get everyone together.” There was some bad luck in the lives of the group members. The first and third week L was not present due to illness and an accident with a skateboard. I compensated for the first week’s absence by designating some extra time the second week to integrate L into the newly formed group. She was introduced and had a chance at the beginning to talk about herself and ask questions about what had happened in the first session. The third week V was not present as her sister fell ill and it was assumed she would not live. Some of the absence was due to giving employment priority over the research group. The final two weeks, F was absent as she had started working full time. Despite the absences, everyone expressed interest in having all the stories and getting together at the end.

These absences meant that some participants did not hear the individual stories read in the sessions. They were happy to get the stories as part of the book at the end, as they felt they had missed out on an important part of the experience and did not want to miss the stories.

More significantly for the collective story was the loss of F during its compilation in the last session. I visited her separately, on May 1, 2001, to get her feedback about the collective story. Her absence from the last session (as the only daughter caregiver) also made it seem natural to put the collective story in the voice of a spouse caregiver as the remaining participants were all spouses. Although the participants wanted to be present in the research, the absences changed the group process.

When compared to group theory, the group also followed an individual path of development. In relation to Weber’s (1982) four stages of group development, the group seemed to skip the Storming stage of group development. It spent the first two
weeks Forming (meeting each other) and Norming (setting up guidelines for work together), skipped Storming (resolving interpersonal conflict) and spent the last three weeks Working (accomplishing the task of the group). The Disbanding phase really happened in the last week and during the individual, post-group interviews in May. I think that because of the short duration of the group, they remained polite and avoided the Storming stage. Outside of the sessions, individual members did express several personal critical impressions of the others. In this way they created secret alliances with the leader. An example of this was when F told me she thought R was overbearing in her opinions and personal manner. These observations would probably have lead to conflict and storming had the group met for a longer period of time.

The personal observations that were shared directly in the group were perceived as constructive. As fits with Yalom's (1998) description of group process, the group members taught each other and challenged each other's perceptions during the group process. F indicated she thought for several days about what V had mentioned in relation to the importance of personal time with her mother vs. worrying about her material goods (furniture). She also was surprised into thought by V's question about where F would chose to live if her mother died (Interview, May 1, 2001). V gained comfort from R's idea that her husband had lived a good long life before his dementia (V, The Two of Us, appendix E). L was encouraged by the other group members to see that after the first difficult transition period there was hope that she could get used to her husband living in a care facility (session 2 and 4). R also challenged the other group members to look more closely at their feelings of guilt. Were these feelings real (in that you could do something to make the situation better) or due to unnecessary causes (there was really nothing you could do to change the situation)? These are examples of the learning that went on in the group.

At first I was concerned about the type of teaching that was taking place in the group. The participants were teaching what they knew (i.e. about grief and loss) and sharing opinions with each other. I clarified in the session that opinions are valuable, but that each person has to choose what fits for them. I also felt that the participants were looking to me for advice, as the expert, at the beginning of the group. I
mentioned some information from studies I have read, and related some experiences I have had in other support groups, but I wanted to make it clear that each person in the group was an expert due to their experience. As the basis for the research, it was important to hear what each participant had to say. This brings us back to teaching and opinions. I found that both had a helpful place in the group process, as long as they were shared with respect (Journal, March 1, 2001).

Normalization was another significant result of the group process. Normalization is the idea that learning how other people experience an event can lead to the realization that certain feelings and reactions are often normal to that event. As can be seen in the themes below, the group members had many common experiences and feelings. All group members at one time or another in the sessions also indicated how helpful it was to know they were not alone in their experiences. The most lively times in the group sessions were when the participants had unstructured time to talk. This is an example of Yalom's (1998) concepts of reduction of isolation and the development of group cohesion. It was also evident that seeing the members who had experienced more of the caregiving arch was helpful to the group members who had not gone through as many of the phases of caregiving. It brought them hope. R and to some extent V had lived through the institutionalization and death of their spouse and they were both still living fairly well.

At the beginning, when sharing their situation, the conversation often focused more on the situation of the family member with dementia than on the caregiver. How the caregiver was doing came to light later in the conversation. It was my intention to focus the discussion on the caregiver. The support group is a place for the caregiver to talk about themselves (session 2). For the caregiver’s it was important to talk about their family member first. It may have been less threatening to begin talking about someone other than themselves. It also may be that the caregivers put themselves into context first in relation to their family member. It was not possible to understand the caregiver without knowing how her family member was living.

There were alliances between group members which shifted throughout the group. V and L were allied in being spouses who had recently 'lost' their husband to a
care facility. R and F allied in encouraging people to take time for themselves. V, L, and F allied about feeling guilty that they could not do enough as caregivers. These alliances were somewhat influenced by the stages that each caregiver was in. The alliances reflected how the caregivers made sense of the boundaries of caregiving. They also reflected the immediate goals of negotiating the caregiving process (session 2).

The 20 minute writing exercise brought out several impressions and feelings about writing. Only one participant had begun writing her caregiver story at the time of the exercise (the second meeting). R said "I am too busy to write". V said "I have one paragraph. I am not an eloquent writer. I have to be in the right mood to do it." L said "She is giving us homework." This implied in a playful way that the exercise of writing was hard work. R said "If we write these stories we will be writing her thesis for her." There was a feeling that it is a challenging task to write your personal story. I made light of the teacher/student dynamic I felt was developing. I encouraged them to write non-stop for 10 minutes to see what happens and get the ball rolling. While they were writing I offered them tea. Two of the participants took the tea and began chatting. Talking is what they would really rather be doing. I said "I did not intend for the tea to stop you from writing." They laughed, and we finished the group with half the people scribbling away, and half the people talking. It was an example of my agenda vs. the agenda of some of the group participants (Session 2).

Session three was the beginning of sharing the individual written stories. In general, the tone of the group changed in this session. It was the first day that we read narratives in the group. The tone was less warm and 'Kaffeeklatch'; more work and performance oriented. Is this the nature of the story-telling? Or of how I set it up? My assumption about sharing stories is that it is healing, as it allows the expression of a personal voice. Instead there is risk and performance anxiety. A warm atmosphere may hinge on acceptance of the person in the story. The fourth session had a more relaxed interpersonal atmosphere. The participants were more familiar with sharing their writing in the group.
Interpretations of the Individual Stories

I have called the third memoir Telling Secrets because I have come to believe that by and large the human family all has the same secrets, which are both very telling and very important to tell. They are telling in the sense that they tell what is perhaps the central paradox of our condition - that what we hunger for perhaps more than anything else is to be known in our full humanness, and yet that is often just what we also fear more than anything else. It is important to tell, at least from time to time, the secret of who we truly and fully are - even if we tell it only to ourselves - because otherwise we run the risk of losing track of who we truly and fully are(, and) little by little come to accept instead the highly edited version which we put forth in hope that the world will find it more acceptable than the real thing. It is important to tell our secrets too because it makes it easier that way to see where we have been in our lives and where we are going. It also makes it easier for other people to tell us a secret or two of their own, and exchanges like that have a lot to do with what being a family is all about and what being human is all about. (Buechner, 1992, p.317)

In this section of the results, I will analyze each participant's story for themes of caregiving that were significant to each of them as a caregiver. Each narrative had the symbolic thumbprint of the author. The individual narratives are personal constructions of the 'real thing' which were presented in the group for honest acceptance. The following descriptions depict some of this individuality. All quotes in this section, unless otherwise noted, are from the story under discussion.

A Moment in Time.

F wrote A Moment in Time. She was the youngest member of the group, in her early fifties. She is divorced and has a son and daughter. Both her children are in artistic professions. F is a naturalist by profession. She strikes me as a competent and active woman. She is insightful and often commented on the process in the group. F has been caring for her mother for 3 years.
Family dynamics and unfinished business are strong threads through F’s experience. She still has several roles which she mentions in the narrative. First the roles of daughter. “The roles have not really changed. In other words, I am still the daughter who makes all the mistakes, and she is still the controlling and domineering parent.” She further reflects this point of view when she notes “I have lots of friends who have grown tired of listening to what is happening with my mother. I think secretly they wish I would grow up.” She describes herself as the picked-on and emotionally abandoned child. From an Object Relations theoretical point of view is seems natural that when she begins to care for her mother, the roles switch, but the unmet emotional needs stay the same (Holmes, 1996; Reeves, 1999). “Suddenly, I was the parent with a spoiled child. And just like my experience with a sick child, my emotions and sorrow surfaced. I felt helpless.”

The narrative reflects several ambiguous feelings about her past and present roles.

I resent that because I am labelled the ‘softie’, I get dumped on. My mother knows what buttons to push to get me riled up. ... I’m resentful my sister doesn’t share the burden, and yet, I’m glad she doesn’t as then I can play the role of the martyr. I am not comfortable as a martyr. As I get older I prefer not to be the victim.

Being the victim seems to mean she has no power over her life. She did not get the things from her mother which her sister did (i.e. furniture). She does not feel in control of her time or planning her life. I just feel I am in limbo. She expresses this when she says “I have the feeling of unfinished business. I can’t get on with life as long as this is unfinished.” It seems there is an ongoing struggle between the triangle of women. The dynamic is one of who has control and what that control looks like.

Part of these dynamics is the role of ‘doing it wrong’. At the beginning F felt trapped by this pressure. For her mother being in a care facility is like a prison, and for F the relationship itself is a prison. This is expressed when her mother says things like, “I worked hard all my life and I don’t deserve to live like an animal in a cage.” Later in the interview, we discussed the sentence “Friends feel they could have done
more for their mothers." When I asked her "What do you think about how much you do for yours?" She felt she is now conscious about what she does and when she does it. It is a active choice she has become more comfortable with. (Interview, May 1, 2001)

F is very clear and open about her feelings throughout the narrative. When her mother is first taken to hospital she feels shock and compassion. She says "My heart went out to her," and "the breathe (was) knocked out of me." Later she felt alone and angry. Her sister "made a quick exit and has continued to do so since." She is sad and frustrated most of the time. The blame often rests with her mother for not planning better, and for being critical. "My mother put me in this situation, because she did not get a power of attorney." When she first attempts to deal with her emotions by seeing a counsellor, the problem (of hurting, sorrow, being in limbo, loss, anger) "wasn't really addressed." There is an ongoing upsetting emotional dynamic which leads to her wish that her mother was more severely ill or dead. This, in turn, leads to guilt and shame. The strongest feelings in her narrative seem to be anger and guilt.

Overall, the general theme is a profound unhappiness with the relationship, with the situation and with how these impact on daily life. This dissatisfaction is ameliorated towards the end of the story. A shift is also evident in the discussions in the weeks following her reading in the group. She begins to come to terms with some of her roles and feelings.

The metaphor of performance and theatre pops up throughout F's story. The 'players' are mother and both daughters. F used phrases such as "depending on the audience", "she is a performer", "I have set the stage", "my sister made a quick exit" (stage left?), "my sister was doing one of her numbers", and "I can play the role of the martyr." It seems to fit in with the drama of the family.

The image of Cinderella came to mind when I read F's story. Her story includes the child who works so hard with no appreciation, the demanding and mean mother, and the evil sister who gets everything. She may have found a way to give herself a glass slipper.

As a caregiver, I have set limits and learned to treat myself so I don't get pulled down to a level of ill health. In order to survive, I have to consciously resist the
wave of helplessness and depression brought on by being exhausted, frustrated, tired, and self-recriminating.

An Unexpected Sadness.

L wrote An Unexpected Sadness. She is a slight, but tall, woman in her seventies, with sparkling blue eyes and well groomed silver hair. She has been a housewife all her married life. She and her husband have been married for 58 years. They have three boys. One of her sons lives in Vancouver. She also has contact with her son in Toronto often, who is married to a Physician. L suffered several accidents during the research period. She missed one session after she was hit by a skateboarder and had 16 stitches in her cut ankle. We had a few cups of tea at her house over the course of the research period (due to the fact that she missed two of the meetings), and the word which comes to mind when I think of her was gracious. She has been caring for her husband for 7 years. He was diagnosed with vascular dementia after complications from heart surgery.

Although L's narrative, An Unexpected Sadness, is short and focused on the progress of the dementia, there are hints at the meaning of the caregiving experience for her. She says "Finally, because of my health, I had to make the most difficult decision of my life. Long term care for (my husband). ... I feel empty inside." These short sentences allude to the grief, loneliness and depression which were the centre of her narrative in the support group.

L placed her husband in a care facility two months ago and has had a very hard period trying to deal with the feelings of loneliness and sadness. She started taking depression medication a few weeks ago. L brings her husband home as often as she can (about once a week). He does not want to go back to the care home when he is with her. She would like to move him home again, but knows that she is not in a healthy enough state to care for him (session 2).

Her most eloquent expression of her loneliness came when she told us a story about her son.
Not long ago I jumped into my son's car, I think I told you that, I said, 'Can you take me home with you?' He said 'How are you going to get back?' He lives out in Coquitlam. I said 'Oh, you wouldn't drive me back would you?' He said 'Well I've got some studying to do mother... Oh hop in.' So we started. I thought 'Oh poor guy, he's really, his mother is really pressuring him.' But oh my god, I couldn't stand it. (session 4)

She also expressed some confusion about her present identity in the transition of sending her husband to a care facility. When L relates to her husband now she is looking for "connection", but leaves "feeling empty". She was surprised when she reflected on what she has been doing as a caregiver, where she has put her energy, and how this affects her Self. "I have lost my own personality. All I'd been doing was (my husband). I thought I'd been doing other things. Who am I anyway?" (session 2) During the course of the research, she began to accept that it may be better to leave her husband in the care facility. She missed him, but moved towards the opinion that it was better for her to continue living alone. In session 4 she said "(silence) I don't know that his quality of life has changed so much. Actually, really, as far as both of us, its getting better. Because I've started to feel better and have more time." She was in the most difficult period of adjusting to the separation during the months of the research group.

The Two of Us.

V was the author of The Two of Us. She is a short, well-dressed octogenarian. She has been caring for her husband for the past 3 years. I will let her introduce herself:

Life began together (with her husband) 60 years ago this month (March, 2001). ...We were married in London, Ont. March 28, 1941. Then there was the family. 5 children, now 17 grandchildren, 11 great-grandchildren. With the usual ups and downs and in and outs of raising school children - then teens - the bills, the housing and some very serious illnesses.
Relationship and connection are strong values for V. She was the social convenor for the group. This emphasis shows in relation to her husband as well, when she writes “Right from the start we were committed to one another. He is the only love of my life and the same for him. Our only separation was through the war years: We built our lives together; we stayed together, played together and prayed together.”

V was very grateful for the external support she received from her social worker, Doctor, respite facility, and God. “I can’t express how much everyone helped me (especially the social worker).” “I was amazed and thankful how God had intervened with all this. I was so weak, dreading the move. It was all done for me.”

She missed the communication she had with her husband, but has adjusted to living separately from him about a year after he moved into a care facility. She felt the period when he lived at home was very hard.

When he came home he started pacing back and forth, in and out of the apartment. Never sitting down for meals for 2 minutes. We stopped socializing. I had to run after him because he wandered away. I was totally exhausted. It seemed to me our lives were falling apart. I was so nervous and frightened, and cried all the time. I couldn’t go out and leave him alone. If I took with me, I was constantly watching him in case he wandered. I couldn’t focus on daily tasks for living. The poor man was so sick and I was so exhausted I was no help. In particular she had to learn new skills to take care of the household.

“Because my husband was not competent to be handling the finances, I’d never done it before - he left me in a mess.” Emotionally she expressed that period as follows:

It's hard to put on paper the emotional stress; the denial, the crying, confusion, pain, arguing, yes even fighting at times, then the love and forgiveness, the loneliness, the family denial, crying out to God “Why us!” Then blaming God, even cursing him. Then find forgiveness and peace in the solitude of God. Having to take hold of our lives and situation. Without Frank beside me. No communication. Every thing just went over his head. ... I was like a zombie. I couldn't focus properly.
In general, the theme of V’s narrative was coping with how the disease meant a huge amount of “loneliness and responsibility (that was) put on my shoulder.”

Caregiver at Heart.

R wrote the narrative Caregiver at Heart. She is a powerhouse of a person. She has a strong voice and is very thoughtful about her experiences. R is in her late sixties, and has two children. She and her husband are originally from Finland, but they have lived in Vancouver for 50 years. R was caregiver to her husband for 7 years. He died a year ago. His death came a few months short of their 50th Anniversary. R recently remarried.

One main theme of R’s narrative was putting her caregiving years into perspective. She had gone through “it all,” and wanted to clear away unfinished business from the caregiving experience. She was the most circumspect in the group and had obviously spent a lot of time thinking about the topics discussed. Because of her personality and the fact that her husband had died, she was perceived by the other wives as an expert. This meant she was asked for her advice several times during the research meetings. At one point, R made a comment about the other group members. She said “I can sympathize so much with where those women are at. I was there. And I feel so bad, because I know it is hard now, but it is going to get worse.” (interview, March 8, 2001)

Several times in the narrative and the discussions R mentioned the mistakes which professional caregivers made when providing support. She was not pleased with the service of one of the home support workers, or the physical care her husband received in the first care facility where he lived. She also was upset by both a counsellor (off-duty) at church and a Director of Care who did not validate her feelings and gave her advice. She was disappointed about the fallibility of the professional support workers and how these experiences left her without support.

The strength of her conviction that life is valuable was the driving force of her experience as a caregiver. As the title suggests, she described herself as having been a caregiver all her life. Through her caregiving experience, personal reflection and
group experiences she has decided to approach her caregiving differently. She felt that as a primary caregiver to her husband she carried the responsibility too long. She felt her old pattern was sometimes one of "excessive caregiving" (session 5). This insight has been a driving force for her transition to new caring relationships.

**Similarities and Differences of the Group Participants**

**Differences between the participants.**

Each participant had a different role in the group. When analyzing the transcripts and the stories, I created titles and motos for each member which I then checked with the group. R was the experienced leader whose motto seemed to be "It was hard, but I did the best I could and don’t regret it." V was the friendly one; the one who connected everyone. Her motto seemed to be "We have had a good life although we are apart. I am glad I did not have to make the decision to separate us." F was the curious one in the group, who felt in relation to her mother "I can never do enough to be loved." L was confused with grief. She seemed to say "This is all wrong. I can’t accept it. I feel sick. This is just all wrong."

Because of these different roles and the various phases the participants were in, each person contributed an important perspective to the research and to the group. R had been in the bereavement phase for one year. V had been in the institutional phase for one year. L was adjusting to the separation of the institutional phase after moving her husband a few months earlier. F had been in the institutional phase for several years, but her relationship was one of parent care which separated her somewhat from the others. In session one, F summarized the personal 'space' of the three participants. "R is grieving and moving on with her own life. V is 'in limbo'. She is not in her normal marriage and she is not single. So, she is not having her own life." F (after I reflected the question back to her) said she is "living her own life, but she is feeling her mother’s pain, and loss of independence; both of which lead to feelings of guilt."

The onset of the family member’s dementias also varied with each case. For V’s and R’s husbands the onset was very gradual. R felt it was emotionally very
difficult to watch her husband lose his memory, and know that he knew it was going. In L's case her husband's impairment was immediate, as the result of a stroke during surgery. F's mother, on the other hand, seems to have improved since she moved to a care facility. This difference may have an effect on caregiver burden and acceptance. Lingering uncertainty has been found to be difficult on the family (Garwick, Detzner, & Boss, 1994).

Another difference was the varying amount of inclusion that the group members felt due to their attendance patterns. L indicated that although she had missed two sessions, she felt she was included and connected to the group members. V felt a loss that she had missed one session, but did not feel a lasting disconnection from this (session five). F felt some separation both as the only daughter caregiver in the group and from having missed the last two meeting due to work (interview, May 1, 2001).

A final interview.

As I collected F's insights about similarities and differences separately from the rest of the group, I am presenting her results independently from the rest. I have decided to do this for two reasons. First, although the relationship of the caregiver to the family member changes regardless of the familial relationship, during my last interview with F, it was important to me to ask if the fact that she was the only person doing parent care in the group effected her feeling of inclusion in the group. Second, F missed the final two meetings of the support group due to work commitments. This also changed her inclusion in the group; especially in the communal story. I interviewed her at home to get her input into the story and the group in general. It was a closure session for her in the research project. I asked her the same questions as the other participants to finish the group meetings.

Then we looked at the communal story the group had created. I was interested to get her feedback on the story for two reasons. First, it was written in the voices of a spouse. In the third group F said she felt like she had the responsibilities of a spouse without being one. "In some ways, my mother treats me like a husband." (Session 3) When asked to expand on that, she said she was expected to be a constant personal
and logistical support. This did influence me in writing it from the spouses point of view initially. However, I wanted to know if she still saw herself in the story. Second I wondered if she still felt she was a part of the group although she was contributing to the communal story outside of the group setting. We approached these questions by answering the questions of similarity and differences of herself and the group.

How were your experiences similar? What did you have in common? F saw five areas of similarity. Dependence of the family member on the caregiver was the most significant similarity for her. “A chunk of you is always directed away from yourself.” A sense of being on hold and not being able to make long term personal plans was another similarity. In week two, V asked F if she would stay in Vancouver after her mother died. F said “That really got me thinking. It had never occurred to me that I could move anywhere.” The possibilities expanded dramatically when she thought about planning life without caring for her mother. Grief was also a similarity. She started the grieving process when her mother was admitted to the hospital the first time. It was a feeling she identified as part of the group as a whole. She grieved for her mother. She also grieved for herself and the type of choices she may have had if she was not a primary caregiver. This followed into a fourth similarity between group members. F felt ambivalence about her mother’s future death. She had “joy from relating to my mother”. She also felt “I’ll die before my mother. ... I am caught in a web where there is no out.” I asked if she felt trapped, but she said she did not. It was something she had accepted. Finally, the constant sense of responsibility for another human being was the last similarity she mentioned.

How were the group members different from each other? F focused on her differences from the other group members. Obviously, she was a child of the person with dementia while the others were wives. This also meant that the loss for her was not one of a lover, as it was for the wives in the group. She felt fortunate that her mother was at that time not deteriorating physically or mentally. So F felt this positive plateau was a difference to the constant deterioration of the other’s husbands. A third difference was the outcome of caregiving to her financial independence. She assumed that when the husbands of the group members pass away that the wives would be
financially stable and independent due to their personal estates. In her situation, because of difficulties with her sister, there was not much left in her mother’s estate to inherit. She did not feel she would be financially compensated for being a caregiver. The issue of the spouse’s financial independence was never discussed in the group, with the exception of having to take over the financial duties. However, F’s expectation that the spouses would be secure was enough to make her feel separated from the group.

When I asked her if she could hear her experience coming through in the communal narrative, she gave me positive feedback and said she could hear parts of herself in the narrative. The similarities she mentioned (dependence, life on hold, grief, ambivalence of death, positive visits, physical and emotional strain, and constant responsibility) are all present in the collective narrative which I and the other participants put together.

**Similarities of the participants.**

There were many similarities in the participants themselves and their caregiving experience. They were all adult women who loved their family member, and wanted the best for them. They had all been primary caregivers for several years. They were also all motivated to look at their experiences in a group context and contribute to the research in the field of caregiving. A more detailed look at the similarities found is outlined in the section of major themes found in this study.

**Themes for the Collective Story.**

It is easy to sum up other people’s lives, ... and necessary too, of course, especially our parent’s lives. It is a way of reducing their giant figures to a size we can manage, I suppose, a way of getting even maybe, of getting on, of saying goodbye. The day will come when somebody tries to sum you up the same way and also me. Tell me about old Buechner then. What was he really like? What made him tick? How did his story go? Well, you see, this happened and then that happened, and then that, and that is why he became
thus and so, and why when all is said and done it is not so hard to understand
why things turned out for him as they finally did. Is there any truth at all in the
patterns we think we see, the explanations and insights that fall so readily from
our tongues? Who knows? The main thing that leads me to believe that what
I've said about my mother has at least a kind of partial truth is that I know at first
hand that it is true of the mother (person) who lives in me and will always be
part of who I am. (Buechner, 1992, p. 319)

Analyzing for themes in the caregiver’s experience was a way of summing up
their lives. It was not with the intent to reduce figures to a smaller size, but to provide
rich descriptions of the truths of these caregiver’s constructed lives. There were 5
major themes that emerged from the narratives and discussions of the group. These
major themes included 14 other categories describing this research group. The first
major theme was struggling with practical aspects of caregiving. This included the
categories of the difficulty of diagnosis, caregiving at home, and negotiating life with a
care facility. The caregiver’s life in community was the second theme which emerged
from the study. It discussed different types of social support, the influence of family
dynamics, and putting the caregiver’s personal life on hold. The third theme
addressed the caregiver’s health. This included the physical and the emotional
experiences of caregiving. Fourth was the theme of shaping caregiving in the
research group. The benefits of caregiving and self care were categories within this
theme. The meaning of caregiving for the participants came through here as both an
overt and a covert theme. It included several diverse topics. The categories in theme
four came particularly from thoughtful discussion in the group. The fifth and final
theme describe the research experience itself. The categories here were writing and
sharing the narratives in the group and the support group experience. These are
themes about the research method and the participant’s impressions of it. Many of the
major categories encompassed interesting sub-ideas, experiences and insights. It is a
misnomer to relegate these to the category of minor themes. Which brings me to a
further observation that the themes found here are not hierarchical in terms of their importance and presentation.

As much as possible, I have used the caregiver's own words to present the themes below. For some of the concepts, I illustrate the idea with examples from each participant. Other concepts are described using the most descriptive example as presented by one or two of the participants. These concepts were the basis for the collective narrative.

**Theme One: Struggling with practical aspects of caregiving**

The first theme addressed the daily challenges at different stages of caregiving. It began with the moment of diagnosis as a pivotal point for the participants. The reality and challenges of caregiving at home followed the initial diagnosis. The caregivers then described aspects of working with a care facility after their family member had moved into long term care. This theme finished with the changing definition of respect for and protection of the family member with dementia. These are examples of the practical changes the caregivers experienced during their caregiving career.

**Moment of diagnosis:** When the participants presented their narratives and background in the group, the moment of diagnosis and the difficulty of this revelation were sighted as significant experiences. It was a moment of change in their families and the beginning of their being named Caregivers. The diagnosis was greeted with shock, sadness and denial. The participants describe the experiences in the following passages:

It was three years ago that my mother was brought to Emergency by my sister and was subsequently admitted after tests revealed a stroke and dementia. Life and daily living for my mother changed then, as it did for me too. ...Now I have set the stage, I can now explain my inner feelings when I was suddenly aware that I had become a caregiver to my mother. The staff had to physically restrain my mother and directed me to go home. My heart went out to this helpless woman. She was so frightened and confused. Her eyesight was
affected and she saw things differently, i.e. her fork was a spoon. My breath was knocked out of me. (F, A Moment in Time, Appendix E)

V wrote about the period of difficulty and receiving the diagnosis of Alzheimer’s Disease for her husband:

I first noticed a complete change in my husband’s personality 3 years ago. He became irritable, suspicious, forgetful, very agitated at me with no motivation. He had loved his computer and just wouldn’t use it. He started pacing back and forth, back, forth. Never sitting for 2-3 minutes. I finally took a list to the Dr. of all the changes. Over a period of time and tests he was diagnosed with Alzheimer’s Disease. I was completely devastated. (V, The Two of Us, Appendix E)

R wrote as follows about the period when her husband was diagnosed with strokes and dementia:

When the illness started, I realized that something was seriously wrong, but my husband didn’t. ...One Sunday morning, he wasn’t able to get out of bed. I called the ambulance and he was taken to the hospital. But, you see, by that time it was too late. The strokes had been going on for some time. It was too late to try to prevent them. After that, the caregiving really started. ...Little by little my husband’s health deteriorated as the years went by; 7 years in all. ...And my hope was that maybe the illness would even go away. We were praying a lot. However, it was wishful thinking. (R, Caregiver at Heart, Appendix E)

For L, the title of her narrative, An Unexpected Sadness, indicates how the diagnoses and disease affected her. She also wrote:

I had a sinking feeling things were not right. ...This began a series of mental evaluations. After a number of tests, the conclusion was dementia. Something happened during surgery. A stroke or lack of oxygen to the brain. From then on things changed. (L, An Unexpected Sadness, Appendix E)

The moment of diagnosis was a moment of change in the lifestyle and identity of the caregivers. It was a clear indication that the relationship and the meaning of the
families' lives together were entering a new phase. The caregivers reacted with both optimism and sadness.

Caregiving at home: The participants described caregiving at home as an experience that became more difficult over time. Two particular aspects were the difficult behaviour of the family member, and how the caregiver did not notice how sick their family member really was. First, when describing caregiving at home the participants described how the dementia caused the family member to engage in some challenging behaviours. V wrote:

When he came home he started pacing back and forth, in and out of the apartment. Never sitting down for meals for 2 minutes. We stopped socializing. I had to run after him because he wandered away. I was totally exhausted. It seemed to me our lives were falling apart. I was so nervous and frightened, and cried all the time. I couldn't go out and leave him alone. If I took him with me, I was constantly watching him in case he wandered. I couldn't focus on daily tasks for living. The poor man was so sick and I was so exhausted I was no help. (V, The Two of Us, Appendix, D).

Some of the behaviour was compared to how young children behave. This increased as the disease progressed. For group members, this behaviour was indicative of the need to keep constant watch on their family member. Trying to maintain that level of control was exhausting, but the participants felt it was necessary for the well-being of the family member. L and R described an example and its effects in the following passage:

L. "He's just like a little kid. If I get on the telephone, he'll get into stuff, like the kids used to do when they were small. He'll get into, oh, maybe crackers, or I bought a jar of mayonnaise ... And he's cagey about it. ... Cagey, I don't know how he does it. I said 'Where are you getting this?' He said 'I don't know.' So then I hid it in a more hidden place. He's absolutely incorrigible about doing things like that. And those things will drive me crazy."

R. "Yes, that's what's going to wear you down."
L. "Yes, it just drove me crazy when I’d get on the phone. He’d get into jam, he’d get into anything - peanut butter, it’s not the fact that he’s eating peanut butter. You know, ... if I took a bath... That’s one thing, I’m glad he’s out of the house. I can take a bath without wondering what the heck he’s doing, you know." (Session 4)

Coping with challenging behaviours was an ongoing learning process for the participants. It changed the relationship of the caregiver to the family member by adding an aspect of control and discipline which was not present in their previous life together. It was a source of surprise for the participants that their family members would act in ways so different from before. This had an impact on both the meaning of the relationship and the sense of self of the caregivers as it added a new dimension to the caregiver’s relationship to their family member.

The second aspect of caregiving at home was a shift in the caregiver’s perspective. The participants said they got used to sickness. The effect was that they didn’t notice its severity at the time. V mentioned this in session 2, and R and L described it in session 4:

R. "Well, I found a picture of my husband. I used to bring him home. He was in his wheelchair. I found a picture that was taken 6 months before he dies. He was so sick. Like he was so skinny and everything else, I thought, I didn’t see him like that, you know I really didn’t. And I thought if he really looked that sick, he must have been, but we see with different eyes. I was glad as long as he was alive, but looking at that picture I also realized, he couldn’t have hung on like that, like this was 6 months before he actually died, and he already looked like a corpse you know, it was awful. But so strange I didn’t see it at the time, you know, I. . . ."

L. "You get so used to it."

R. "Exactly you get so used to it."

L. "I used to look at my husband and I didn’t notice he was turning yellow (hmm). When the doctor saw him he just automatically put him in the
hospital right away. It has something to do with his kidney, and I thought, yah, he does look kind of yellow." (Session 4)

This limit of perception may have a significant effect on the caregiver's ability to make a decision about when she can no longer keep her family member at home and when it is time to move him to a care facility. My assumption is that it is too much burden for one individual (particularly and elderly one) to care for a person in the later stages of dementia alone at home. Unless extensive home support and the necessary physical equipment can be provided at home, eventually the person with dementia must move into extended care. As professionals providing support, it is important to respect the caregiver's ability to make their own decisions. This theme from the group is important in helping primary caregivers make the best decision. At the least, however, the insight that the participants can lose sight of the severity of the illness may have an effect on their perception about how they care for themselves.

Negotiating life with a care facility: The decision of the participants to move their family member into long term care was a difficult emotional one for all of them. The decision involved assessing where the family member would be provided with the best care (at home or in a facility) and how the caregiver could deal emotionally with the separation.

During session two the group discussed the difficulty and timing of when to move a family member into a care home. V and R both said that in hindsight they waited too long before moving their husbands into a facility. They and their husbands would have been healthier if the move had been made earlier. V said she had heard that moving in earlier helps with long term adjustment. R felt that the combination of care (from the spouse and the facility together) was more complete. They also said that, in their experience, taking their husbands home too often was unsettling for them and prolonged the period of adjusting to the new situation.

The caregivers did however feel that they could, at least in emotional ways, provide the best care to their family member. They had time to be attentive and knew the person with dementia better than any one else. This allowed them to care better than a professional stranger (session 2).
F asked whether the women took their husbands home for their sake or for the sake of the husbands. R said it was for both. The emotional transition of letting go of their life in the same house, and the loneliness were significant factors. This was the situation L found herself in during the research period. The group members were empathetic to L's immediate struggle and gave her some perspective on how the situation may turn out in the long term (session 2).

L struggled with the decision she had made to move her husband into a care facility. She expressed her worry and ambivalence many times. This is one example from session 4 where she wondered if her husband would be more active if he lived at home.

He's inclined to stay in bed, but he did go to adult day care four times a week. So he had to get up and go to that. It kept him quite active, that's why I think that in a way that was better than what he is doing in this long term facility, because, but I'm half scared to get him back home, you know, I don't think I'm quite ready for it, but then I think, 'Will I ever be ready for it?' It can go, like you say, eventually you get tired again and you start all over again.

The decision to move a family member into the care facility is sometimes taken out of the caregiver's hands. This was the case physically and metaphorically for V. She was "at the end of her rope" and had her husband taken to respite for a weekend. During that time she fell and shattered her right arm at the wrist. She was in the hospital for 3 weeks, and had a bone graph from her hip to her arm. Her husband stayed in a crisis care bed at the hospital until her cast was removed. It became clear to her during her convalescence that she could not care for him at home any more. Her sister and daughter came for moving day and helped him move into a room at a secured care facility. V could not make the decision alone. She said, "This was my life." It was like ending the marriage in some way. In her view the Lord made the decision for her at the right time (Session 1).

The timing of the move into long term care had important implications of meaning for the caregiver. When the family member moved reflected on both the relationship of the caregiving dyad and the competence of the caregiver. At the time
the person moved, the participants remember two meanings. For the wives it was like ending the marriage. They were physically separated after decades of living together. For F (a caregiving daughter), it was move difficult to accept the loss of independence her mother experienced in the care facility. Her parent was no longer capable (Session 2).

As both the caregiver and the person with dementia had time to adjust to the new situation, the meaning changed. The marriage relationship took a new form. The person was still a husband, at least in title. The caregivers experienced a chance to physically recuperate, which improved their physical, cognitive and emotional well being (Caregiver at Heart, The Two of Us, Session 5).

This adjustment and acceptance did not take place for F’s mother. When V reflected that her husband had now adjusted well to his new place, F was startled by the word “adjusted”. She found it interesting that V and L expected that of their husbands. Her mother has adjusted physically, but not emotionally to living at the home. The group members were surprised that F’s mother still resists after 4 years. V commented that “not adjusting” was a feeling that could keep F’s mother motivated in life. F laughed with some ruefulness at the remark. It was a point that made her life difficult at that time (Session 2).

Despite this, F had found some acceptance for the situation.

Life is the way it is today. The clock cannot be turned back. If I give her moments of pleasure by singing with her and visiting, I will have helped the time to pass for a free spirit, non-conformist, Margaret-Thatcher-in-disguise mother.

(F, A Moment in Time, Appendix E)

She found meaning in supporting her mother’s independence, even after her mother moved in to the care facility.

A second aspect of negotiating life with a care facility was how the caregivers interacted with their family members and the facility staff. The participants described moving into a routine of visiting their family member often in the care facility. V visited her husband several times a week at “his pad,” and he occasionally comes home to “her pad.” He had adapted to having his own place. “He has been at the residence for
1 year now. He is doing well under the circumstances, with proper medication and
good care, regular meals and no responsibilities. He is in a constructive environment."
(V, The Two of Us, appendix E) R wrote “I still went there most days to feed him and
take him outside. He loved the outdoors. I could tell he knew when we were outside.”
(R, Caregiver at Heart, appendix E)

Not all the experiences with home care and care facilities were positive. R
mentioned that the home care staff who came before she placed her husband in the
home were not as competent or trustworthy as she was. For this reason, the first time
she moved her husband into long term care she moved him back home.

A bed opened up for him in a care place. I had him admitted for the first time.
...However, after three and a half months I decided to bring him back home,
because there were things happening at the care place that made it a bad
experience. The attitude of the staff was that they owned my husband. They
actually said ‘We are his family and this is his home.’ I strongly disagreed. (R,
Caregiver at Heart, appendix E).

She did balance this with the opinion that “Going to respite helped my husband
get used to being in a care place. This helped tremendously when he ended up in a
care place permanently.” (R, Caregiver at Heart) The consensus of the group was that
it was important to pick a care facility with caution. They valued respectful, competent
care where the caregiver continued to be included in the life of the person with
dementia.

Protection and respect: A fourth issue for the caregivers when looking at the
theme of practical aspects of care was the issue of protection and respect for the
person with dementia. This issue was present throughout the various phases of
caregiving; from diagnosis and care at home, through the institutional phase and in
bereavement (as seen in R’s experience with the Director of Care - see the section on
hurtful advice). The following segment of the session describes the challenge of
providing protection and remaining respectful while the family member is still at home:

L. “And he has gone down in the basement. Now that’s dangerous. In
fact he went down last weekend. I said ‘What are you looking for
down there?' I was looking for a beer.' I said, 'There's nothing down there.' He could very easily fall. He can't get up unless he comes up on his hands and knees. I said 'You're going to kill yourself going down there.' I said. He didn't answer me.”

R. “What I did was, like our house was old, so I got one of the keys, and locked the door. He was asking for the key, but I said no, because they can fall. And then if he brakes his leg, you know…”

L. “And when I leave him in the car, sometimes, when we're shopping he's tired. This was a while back, I would think then how I'd always take the keys out. Because I thought you never know what might get into his head. When he might decide he wants to drive. He said 'You can leave the keys in the car.' (R. That's an indication. ) I said 'Oh its just a force of habit. I guess I'm just used to doing it.' I thought, 'Oh God, that's all I need. See him driving away.’”

K. “You're responsible for his safety.”

L. “Well I mean yah.”

R. “The thing is that its so difficult, when he's been your equal and suddenly you have to start treating him like a child. Like you know you wouldn't leave the keys in your car if it were a child. You wouldn't leave the child period, but you know what I mean. You have to treat him like a child, and that's very difficult. I always felt I was putting him down or something, and yet you have to, because of the illness.”

K. “You felt you weren't respecting him?”

R. “Yah, like it was putting him down and it is very difficult and yet you have to do it. Once the dementia is there they are doing these things. You can't do it like you used to, you know, its just too dangerous. So, and its hard.” (Session 4)

The concern about safety did not completely disappear when the family member moved into a care facility. F found this out when her mother claimed she was being raped. F had worked with the nursing staff on this, but was not sure how she could
prove the allegations one way or the other (session 1). As the primary caregiver of someone who cannot protect him or her self, it is an ongoing problem. The issue of respect is difficult to resolve. After a while, the person with dementia is no longer competent to make decisions for themselves. It is another example of how the relationship of spouse or parent has to change. The meaning of being respectful shifts to include some restricting actions on the part of the caregiver to ensure the safety of the family member.

In summary, the theme of struggling with practical aspects of caregiving outlined four issues of working as an informal caregiver of a family member with dementia. The moment of diagnosis had significant meaning to the caregivers as a moment when their lives were irrevocably changed. Caring for the family member at home brought learning challenges and a redefinition of the personal relationship. Moving the family member into a long term care facility and negotiating life with the facility brought further logistical and relationship changes that involved planning and adjustment over time. Finally, there was a continuing balance and redefinition of according the family member the respect he or she deserves as an adult with the necessity of maintaining his or her personal safety. From the examples presented it is clear that practical aspects of caring had specific meanings for the participants. This was particularly true in relation to changes in the personal relationship of the caregiver to the family member and learning to cope with the disease.

Theme Two: The caregiver's life in community

The second theme which emerged from the research was the relationship of the caregiver to the community. This included three main ideas. The first was the social support network of the caregiver. Some parts of the support network were very important to the caregiver's life. Other experiences of dealing with dementia in society were less helpful. The second aspect of the caregiver in community was the impact of family dynamics on the caregiving experience. This included some changes of roles and some examples where old family patterns remained intact. Regardless, the relationship patterns influenced how the caregiver gave meaning and sense of self to
the caregiving experience. A third issue in this theme was how the demands of caregiving impacted the personal development of the caregiver. This impact was experienced as putting the caregiver’s personal life on hold in some areas.

**Social support:** The issue of social support presented itself in many guises. Some of the concepts which emerged were positive in the sense that the caregivers benefited from the connection. Some of the types of social support were more hurtful and negative for the participants. In general, social support was seen as vital to surviving or thriving in the caregiver experience. L expressed it as follows:

You do, you need support. Its terrible. ...Its like my cousin in the States, she’s had a (few) very tragic (experiences). ... She said she had lots of support. She belongs to a church, and then she has 4 girls, and they are all close around. She had more support than I did, she said. That’s a wonderful help. And I said ‘Yah, I guess so, I can see that’s what you need.’ I do have good friends. I had a friend come over yesterday afternoon. So, but we need support all right. Lots of support. (Session 2)

R was succinct when she said “Its the people that are with you. ...You really don’t need that many people. You know, one or two, or three that are faithfully there for you.” (Session 4) Six aspects of social support came to light in the group process. Support from family members, changes in social networks, professional support, spiritual support, social stigma and hurtful advice all had an influence on the caregiving experiences of the participants.

The help of family members was a topic that came up several times in the group and in the narratives. Not all of the siblings and children of the caregivers lived close enough to provide physical support. Staying in touch through phone calls and help when visiting were common ways these family members supported the primary caregiver.

Some of the relatives who lived close by helped on a regular basis. R said her son took over the yard-work and other jobs around the house. V’s children were also available; taking their father on trips or visiting him often (session 5). L’s son who lived in the area had also been very helpful.
Collective Narrative with Caregivers

(He's) really very good. He's really, I think sometimes he resents being the only one that's sort of ... although I don't know what I would have done if it hadn't been for him. He really has been a good help, but I think it is hard for him to see his father like that you know. (Session 4)

Yet other situations were mentioned where there was no support forthcoming from relatives who lived close-by. This lead to cut-off in the family relationships. R said

I'm sorry to say my daughter was another person. There were some times I asked her, and she could come and stay with her father, um, and she said "No", and the third time she said she would come, and I even made appointments and she never showed up. So after that I thought, you know, I just can't ask her. ... So, I took care of it. It wasn't until the past 6 months that I am starting to phone, and we are talking. (session 4)

Similarly, F's relationships with the rest of the family (her sister) were highly strained. F's sister did not visit anymore, and there had been acrimonious legal battles over possessions and finances. The sister went into their mother's home and "took all the things of value" before anything was settled. This situation left F feeling angry and hurt (session 1).

The importance of family support was evident for all the participants. It was something they all needed and valued. It gave them a sense of continuity and connection. It also gave them needed physical help when caregiving at home. The issue of family dynamics, which is discussed further on, had a direct impact on family support in caregiving.

Professional support was an important aspect of the caregiver's life in community. Reaching out for professional support came through in all the narratives. V describes the significance this support had for her:

In the meantime my Dr. sent me to the counsellor and the Dr. (at the outreach centre). I thought I'd never need a counsellor, but I am so genuinely grateful. This is something I had to face alone, just I. I was frightened and scared.
I can’t express how much everyone helped me (especially the social worker). Week after week she listened to me. She connected me with all the right people. She’d be there for me, make a lot of personal calls to my house. The Dr. too. (V, The Two of Us, Appendix E)

R also wrote that she had to access outside help while caregiving:

The illness got to the point where I could not care for him alone anymore. I needed help. I was able to get him onto a daycare 3 days a week. He could not be left alone anymore. He wasn’t aware of what he was doing. ... The government allows 4 weeks of respite a year. I took advantage of this. (R, Caregiver at Heart, Appendix E)

As seen above, the professional support took the form of respite care, daycare, social workers, counsellors, and doctors who were familiar with dementia and caregiving. The participants negotiated connecting with and making arrangements with many social services and professionals during their time as caregivers. They typically did not seek out this help at the beginning of caregiving, but turned to it as a relief when the demands of caregiving became too intense.

For three of the four participants, spiritual support and the connection to a supportive God was another important part of their community support network. At the end of the first session they touched on how all three of them were Christian (have a spiritual belief), and how important that was to them. This was especially the case for the older women. V said she could not have survived without the guidance and support of the Lord (session 1). In her narrative she wrote “I was amazed and thankful how God had intervened with all this. I was so weak, dreading the move. It was all done for me.” (V, The Two of Us, Appendix E) R also described an incident where she felt God had intervened. It is depicted below:

At some point, due to the diabetes, his foot split open and it became infected. There was a threat of it being amputated. That was a nightmare. I asked the church congregation to pray. The foot gradually healed. All the Doctors said it was a miracle. (R, Caregiver at Heart, Appendix E)
Social stigma and dementia was an idea which decreased the social support felt by the caregiver's. The question of social stigma was addressed by the participants in the fourth session. They felt there was a stigma connected to losing memory and ability. Dementia is a form of mental illness, which are in general stigmatized by society.

R. “Yes, there is (a stigma attached to dementia), not as much as mental illness, but um, because somebody at our church said, when I told them, my husband suffers from dementia, she said, she's a nurse, actually a surgical nurse, so I thought she would have better ideas, her attitude, she said ‘Oh, well most people don’t talk about those things, they keep it a secret.’ And I said ‘Well why keep it a secret, it's just an illness like any other illness, you know.’ It’s very strange. But I think people are starting to come out, you know the more we talk about it, the more we get people to know, you know its an illness, and its nothing to be afraid of or to be hiding behind closed doors sort of thing. ...”

K. “To be ashamed of,...”

R. “To be ashamed of, because I mean it's an illness, it's not a sin that you got for yourself or something like that you know.” ...

L. “It can happen to any of us.” (Session 4)

R and L were specific about describing dementia as an illness like any other. There was a sense that advocacy and publicity were needed to clear up this misunderstanding about their husbands.

In a similar negative vein, there were several instances during the sessions when social support was described as taking the form of hurtful advice. R had two examples of this. The first was in relation to her grief after her husband died. R said:

Like, people that don't know what its like. They can say something, like one said to me ‘Well, snap out of it, don’t feel sorry for yourself.’ 3 weeks after my husband died. You know, you never come up with those sort of things (if you have experienced it). (Session 4)
The person offering the advice was a counsellor. The feeling in the group was that she should have known better than to give such thoughtless advice.

The second situation was at the care facility where R's husband lived. R was upset by the lack of value the Director of Care seemed to give to the death of her husband. It came through during a discussion on the topic of funeral arrangements.

R. "Life is still valuable. Like sometimes people think that the mentally ill, that people like that don't have any value, but they do have value. Life is valuable. And those nurses wouldn't have there jobs if it wasn't for the mentally ill. For one thing. No, everybody's life has value. That's a right.

But they asked me if I had made some kind of arrangements. But the Director of Care she said, I guess they are so used to these things that for them its routine, but she said, 'Make sure you make funeral arrangements. We don't want to keep them here after they die.'"

L. "Oh, god, oh, no."

R. (laughs) "I just, it, the, 'We don't want to keep them here.' That's what really got me. You know. And I made the funeral arrangements. Did they ask you to make the funeral arrangements?"

L. "No, I do have some arrangements made. ... But no, they didn't ask me that, thank god."

M. "But then on the other hand, when the time came, I was grateful. She didn't have to be quite that blunt, but I was grateful that I had done it, because everything is so overwhelming, and when all that is taken care of I didn't have to go into it at all. Its just, how it should be. And so I was grateful that I did it when I did it." (Session 5)

Although the advice was not passed on to R in a helpful way, she excused the Director of Care, by saying the discussion was routine for her, and R recognized that in the end following the advice helped her. Probably the intention of the advice was not to hurt the participants. In general, the state of mind of the person getting the
advice is also important to how it is perceived. Regardless, these examples in the
group were reminders of the importance of giving respectful support.

As a final point under social support and caregiving, the participants described
how being a caregiver brought changes of their social networks. The people who the
caregivers counted as friends shifted during the process of caregiving. Each
participant mentioned one or two close long-term friends who stayed by them, but as
the caregiving experience progressed a trend was seen where participants related
more to other caregivers than to previous friends. For the wives in the group, there
was also a shift from relating mostly to couples to relating to single people. R
mentioned again (as in the second session) that her social support network changed
during the course of the last seven years as a caregiver to her husband.

First the couples disappeared. The friends we used to do things with as a
foursome slowly stopped contacting us. Then after my husband’s death, more
friends disappeared. The people from the church who called every week didn’t
call anymore. I think they were uncomfortable with grief. I was so alone.
(Interview, March 8, 2001)

When participants were still caring for their family member at home, the demands of
caring meant that they became isolated. V said “We stopped socializing. I had to run
after him because he wandered away.” (V, The Two of Us, Appendix E) Since her
husband was now in a care facility, she found she spoke of him mostly in terms of his
dementia. As she and her husband were managers of the building where she still
lived, she had many people asking her how things were going and checking in with
her. This she found to be a mixed blessing. She did not always want to have to talk to
people about the disease. He was “As well as he can be, under the circumstances”.
(Session 1)

Family dynamics: How the family related to each other before the need for
constant caregiving arose did have an influence on the form that caregiving took for
the participants. Although this especially came through in F’s narrative “A Moment in
Time,” other participants felt it had an impact on them as well. The group discussed
previous roles and their effects in session 2. It came up by looking at who had been
the previous driving force in the relationship. The question was from F. She asked the group “Who was the driving force in your relationship before the disease?“ She said her mother was the driving force in the relationship. R said she was the dominant one in her marriage. This continued in her caregiving. The situation for V was that her husband was the one who was the moving force in their relationship. V learned many new skills which her husband had previously been responsible for. L told the group that her husband was very social and outgoing, “He was a presence,” and that their relationship had been equal. The relationship was no longer equal for any of the participants. I did not have an opportunity to ask the group, but I speculate that the driving force may have shifted from fulfilling the needs of a particular person in the relationship to fulfilling the needs of the disease. In that sense the disease is externalized and becomes the driving force in the relationship. The disease is an unwanted and demanding guest in the family (Session 2).

Past family dynamics were one motivation in F’s decision to be primary caregiver for her mother. F describes herself as “never the favourite daughter.” When her mother was moved into the home she was asked by her mother to give her support. F saw this as an opportunity to do something which may gain her mother’s approval. She visited her mother almost daily, and took calls from her “all the time.” (session 1)

After F was finished reading her narrative in session 3, the group talked further about family dynamics. F’s relationship to her mother had been similar since she was a child. She felt she could not do things right. This feeling had continued into her caregiving. The narrative was about anger and guilt. As feedback to F’s narrative, V talked about the fight over material things. V’s impression was that the time with the person is more important than things. My interpretation of the situation was that there was some sense in F of a lack of justice and fairness. It was her right to be accepted and loved by her mother. She spent a lot of time with her mother. It was also her right to get some things as ‘payment’ from her mother (session 3). Again, however, her sister got it all. “My sister was doing one of her numbers and took possession of all my mother’s cash money and prized possessions, leaving the rest to me, ‘to throw away or
In her narrative F noted:

I am very sorry she (her mother) is where she is. I am very sorry I cannot do more for her. I am very sorry I allowed her to influence how I feel about myself. I need to be satisfied that I do as much as I can for her and I must not jeopardize my own health as she will never comprehend what damage she can do to my health. It is never enough. The sauerkraut is always too salty. Mrs. R’s family is so good to her, (inferring I am not good to her). She demands more and more. I try to be cheerful but her negativity wears me thin. The roles have not really changed. In other words, I am still the daughter who makes all the mistakes, and she is still the controlling and domineering parent. My only defense is to go away, as example, going to sea for months. My escape. She survives well. She is relatively safe and her daily needs are met.” (F, A Moment in Time, Appendix E)

In general, changes of the roles in the family were an issue for the caregivers in the group. The difficulty of accepting the deterioration of a parent due to the dementia came up for all of the participants. F said the changes in her mother’s capability and independence were hard for her to adjust to (session 1). It was clear in her narrative that F’s mother was always a very hard-working, strong, and independent lady. “My mother is a self-made woman. …Her drive, common sense, intelligence, spark, curiosity, stubbornness, self-centered, manipulative, love of life made for a very interesting person.” (F, A Moment in Time, Appendix E) Seeing this change was part of the loss and adjustment of caregiving for F.

L and R also described how it was hard for their sons, in particular, to watch their father’s condition worsen.

L. “He really has been a good help, but I think it is hard for him to see his father like that you know.”

R. “…my son always looked up to his father and then seeing him going down like that, he just couldn’t handle it. A reversal of role. Gradually he realized this was happening. … Its not that he respected him less,
he understood it was an illness, but um, He had to let go of the father that he knew, and now there is this sick person.” (session 4)

V mentioned that, although her children are all supportive now, her sons took more time to accept their father’s illness than it had taken her daughters (session 3).

Past roles in general as a caregiver was another issue discussed as part of the family dynamics. All the women in the group felt they had other previous experiences in which they had acted as a caregiver. For the wives the past experiences seemed to lead naturally into this form of caregiving. L said,

I think when you are a mother you are a caregiver and you always, ... when you have kids, you are wanting the best for them, ... and you usually go into it with no experience, I mean I didn’t have a clue about kids when I had them. You stumble along and do the best you can. You love them, dearly. I’m sure there are things I would do differently now, but its a ... I guess you just do the same again (as a caregiver to her husband).

And it always seemed that, when my husband was sick, he would just go to bed and forget everything, ... but when I was sick I still had to remember to ask him to do this, do that, nothing gets done, the house is filthy and then by the time you get up, you feel lousy, and then you’ve got all this to try and catch up on. (Session 4)

V was a caregiver for an ever expanding family and caretaker for the building where she lived. She had been married for 60 years, and had been a caregiver for her husband for 3 years. She had 5 children, 11 grandchildren, and 13 great-grandchildren. She was a homemaker and a mom (Session 1). These were how she described her previous roles as a caregiver.

R defined herself as a caregiver in the title of her narrative, A Caregiver at Heart. “I mean I’ve been a caregiver since day one. I looked after my brothers and sisters in Finland when we were young. ... (and) I was a mother.” (Interview, March 8, 2001).

F, in contrast, cared for her children, but she felt her children had more independence from her than her mother had at the time of the group. For her, the past
roles she had were more the blacksheep of the family and the type of caregiving she did now was not a natural extension of her other experiences.

It is evident from the above descriptions that family dynamics impact the meaning and sense of self of caregivers. In some cases the dynamics had a sense of continuity and in others they were forced to change as a result of the dementia. For one caregiver, family dynamics were a significant motivation in taking on the role of caregiver. Understanding the changes of roles, or the previous experiences of caregiving helped the caregivers' make sense of the present situation. Family dynamics were used to define and describe some of the changes of the caregiver's relationships.

Putting the caregiver's personal life on hold: The concept of having to put your personal life on hold while being a caregiver permeated the group discussion and the narratives. R mentioned that her life focused solely on her husband and his needs (Session 1). It did not leave energy or time for personal pursuits. The exception for her was when her husband was in respite care. F agreed saying that the dependence of the family member on the caregiver was her most significant similarity to other caregivers. "A chunk of you is always directed away from yourself." (Interview, May 1, 2001) This gave her a sense of being on hold and not being able to make long term personal plans. F also expressed her impression of being on hold in her narrative. “I just feel I am in limbo. I have the feeling of unfinished business. I can't get on with life as long as this is unfinished. I dread the passing of my 87 year old mother ....” (F, A Moment in Time, appendix E) V felt she was just getting her own life back, after moving her husband to a care facility a year ago (Session 1). Although she felt more independence, her last words in her narrative were “What do I do now? I have to keep going. Get up and face the day. Wait.” (V, The Two of Us, Appendix E)

Part of this lack of having a personal life was a feeling that the caregiver was completely responsible for another person. The participants were responsible not only for that person, but for all of the household and external activities (such as finances) as well. V wrote “I was like a zombie. I couldn't focus properly. I think they were beginning to think they had 2 seniors on their hands instead of one. ...The loneliness
and responsibility it put on my shoulder.... " (V, The Two of Us, Appendix E). This time in the caregiving process did not leave a lot of opportunity for personal development, with the notable exception of new activities connected to the needs of caregiving.

This intense focus on the family member had an influence on the participant’s sense of self and identity. When L related to her husband after he had moved out she was looking for "connection", but she left “feeling empty.” She surprised herself when she reflected on what she had been doing as a caregiver; where she had put her energy, and how this affected her Self. “I have lost my own personality. All I’d been doing was (my husband). I thought I’d been doing other things. Who am I anyway?” V echoed this when she said, “My Being ties into my husband.”

F asked “Why is that so?” R thought it had to do with having lived together for so long. She said “He becomes so much a part of you.” The other wives agreed. R continued “When he is gone you have to built a whole new life.” V interjected “Which is so scary.” R said after her husband’s death she didn’t cry for 6 months. She heard a woman on a video saying that after her husband’s death her life her life would never be the same again. R realized that it was the same for her. Her life would never be the same again either. “I had known it in my head, but now I felt it in my heart. I cried and sobbed for an hour and a half. Then I started to heal and move on (with my life).” L felt that this new life was one of loneliness and she saw that as very difficult. She said “Being alone is dynamite.” R finished the session with how helpful she thought a support group could be for not feeling alone (session 2).

The largest impact on the sense of self for those participants who were wives seemed to be connected to loosing the marriage relationship. Is this loss intensified after a period of caregiving? Apparently, so. The spouses spent an extended period of time giving her energy to one person. The nature of the disease resulted in less and less being given back by the family member in return. This focus and the transition of loss lead to questioning, as L did, “Who am I anyway?”

In the case of the daughter caregiver in the group, the impact on self seemed to be more about personal worth and physical plans for the future; living a productive life. For example, in session 2, F was asked if she would stay in Vancouver after her
mother died. F said “That really got me thinking. It had never occurred to me that I could move anywhere.” The possibilities expanded dramatically when she thought about planning life without caring for her mother (Interview, May 1, 2001).

Moving towards personally independent activities was one way the caregivers’ changed their sense of being on hold due to their caregiving career. “So now that your family member is in a care home, what would you like to do if you could?” This question brought a playful mood to the group, and there was a lot of laughter during the discussion. V was definite. She wanted to take line-dancing. She knew where and when it was offered, but somehow hadn’t made it there yet. The group encouraged her to try it soon. R was getting married again. This brought congratulations from the group. The discussion moved to romance and companionship. L said she would like male companionship, but was not sure about having a boyfriend. She felt she was too old. The group disagreed with her. They told her it was still a choice she had. The group members had thought about the possibility of new relationships. V and L were still attached to their husbands. F wanted to go whale watching in Mexico. L thought she would like to do some kind of volunteer work, but did not feel she had the strength to do any at the moment. R said she was in the phase of taking time to express her feelings of grief and to move on with her life.

The discussion continued. F asked L if she had considered doing something like taking a cruise. R mentioned that she had done that while her husband was in respite and it had “done her a world of good”. L and V did not think they could afford to take time away. F pushed the question “If your husbands are now being taken care of in a home, why can’t you do other things or go on holiday?” They were held back by the fear that their husbands might die while they were away (Session 2).

I had the sense that L and V felt it would not be fair to have a good time while their husbands were suffering from dementia and in a home. I said “It is not fair that your husbands suffer from this disease. I wonder if you don’t want to take a trip out of a sense of loyalty to them?” The room erupted in discussion. R responded first with the comment “Who said life is fair?” L and V agreed with my comment. R said she did
not feel bad taking time away. It was not at her husband's expense. Before he got dementia he had had "a good life."

He had everything he wanted. Moving to Canada, and job, a wife and a family. And because of the length of the disease we had time to do what we needed to do. We had time to say what we wanted to say to each other." (Session 2)

This left her feeling independent enough to leave him for periods of time in the care facility. V was impressed by this cognitive reframe and said she had never seen the situation in that light before (Session 2).

This difference in willingness to be separate from the family member was in part due to how happy the caregiver thought her family member was in the care facility, and how much the caregiver felt they were responsible for giving her family member a good life. R had more distance than L and V seemed to have at the time. It was a hurdle that F had to overcome as well. She eventually felt she could go away (i.e. for work) as her mother was safe and well cared for, if not happy, in the care facility.

In summary, the caregiver's life in community was reshaped by the experience of caregiving for a family member with dementia. Social support was very meaningful to the caregivers. It took many forms. Some of the caregivers' experiences did not validate them as they coped with the needs of dementia. In general, the caregiving redefined the caregiver's social network. Family dynamics influenced the meaning the caregivers' gave to their caregiving relationship. Finally, the caregivers felt that the necessity to focus a lot of their personal energy and time on the person with dementia left their personal growth (separate from that related to caregiving) on hold. How the caregivers' interacted with the community had an important impact on how they continued to make meaning of the experience of caregiving. It changed how they defined themselves as part of the community.

**Theme Three: Caregiver health.**

The effect of caregiving on the caregiver's health was the third theme which was found in this study. There were two aspects of health that were highlighted. The first
was the physical process of caregiving and the second was the negative emotions of caregiving.

The participants all expressed a belief that too much self-sacrifice was not a good thing for personal health. R spoke several times about her impression that she worked more than was good for her as a caregiver (see self care category). Along similar lines, L and V felt (some time after their husbands had found a place in the long term care facility) that they had kept their husbands at home longer than they should have for their personal health (Session 5).

The physical process of caregiving: Physical strain was one aspect of caregiver health. L and F both experienced physical problems that were attributed to the stress of caregiving. F wrote:

I feel tired. I feel I will die before my mother. She upset me to the point I had to go to Emergency with chest pains. I felt pretty stupid telling the Emerg. Dr. a phone conversation with my mother prompted the chest pains. It was a wake-up call. (F, A Moment in Time, Appendix E)

Similar to this was L experience which she described as follows:
Finally, after looking after my husband for 7 years, I ended up in the hospital. Finding nothing physically wrong, it was concluded that it was a stress related problem. I had continually refused long term care for him. Finally, because of my health, I had to make the most difficult decision of my life. Long term care for my husband.” (L, An Unexpected Sadness, Appendix E)

Similarly, a loss of energy was also a common experience of the caregivers. The participants described the process of caring at home as a time of continually decreasing energy. After the family member moved into a care facility, some of this personal energy returned. Some of the new energy was consumed in the grieving process of being separated.

L said “I was jumping around and full of energy and so enthusiastic, about (it). ... , and little by little my energy drained, gradually , I don’t have very much energy ... there’s no hope for better, but it’s just to have him here...” (Session 4). V expressed the same sentiment when she wrote “I can’t tell you how I felt ... the loneliness and
responsibility it put on my shoulder. I was overwhelmed. The crying began again. ... I was totally exhausted." (V, The Two of Us, Appendix E)

R wrote not only of the loss of energy, but of the transition back towards health after her husband moved into the care facility.

As a caregiver, I started to realize that my strength and energies were used to the max. But somehow each day I had the strength to cope with all of the problems. ... I knew I would have a very hard time, and didn’t know how I would cope, but never-the-less I took him home again. I was able to get him back to daycare, and I also used a weekend respite program. So I was able to sleep 2 nights a week. He would only sleep 2 hours in a 24 hour day. His heart was failing, but we didn’t know. Gradually, I knew I would collapse if I didn’t get him admitted. I got an emergency bed at a care centre. It was a very good place. ... Now that I was also able to sleep my nights I became more like myself. I was more calm. I could get my thoughts together and concentrate. (R, Caregiver at Heart, Appendix E)

Depression was a third physical strain discussed in the group. Even after moving her husband to a care facility, caregiving was continuing to have an effect on L’s health. She was taking anti-depressants to battle a situational bout of depression. In session 4 L said:

I think these anti-depressants are starting to work. I think I feel a little bit better. ... In one way its kind of a - well you might say its a relief, and in another way its sad, … I think probably I’m suffering more than he is, well, if the word is suffering, ... I think these pills are an absolute necessity. .....(for) me, to be feeling better.

R mentioned that she also experienced a period of grief after her husband went into the care facility (R, Caregiver at Heart, Appendix E).

The negative emotional experiences of caregiving: Due to the frequency with which the subject of emotions in caregiving appeared in the narratives and discussion, it is safe to say this was one of the most meaning-filled themes in the group. Specific incidents from the participants were used here to narrate specific negative emotions in
the group discussion. Resentment, frustration, and anger were felt by the participants because of the process of caregiving. Guilt and grief or loss were very strong emotions in the process. Positive emotions such as relief, gratitude and joy were also mentioned, although not until later in the narratives. V wrote:

It's hard to put on paper the emotional stress; the denial, the crying, confusion, pain, arguing, yes even fighting at times, then the love and forgiveness, the loneliness, the family denial, crying out to God “Why us!” Then blaming God, even cursing him. Then finding forgiveness and peace in the solitude of God. Having to take hold of our lives and situation. (V, The Two of Us, Appendix E).

F used the emotions of guilt, sorrow, helplessness, hurt, limbo, loss, and shame to describe how she felt while caring for her mother (F, A Moment in Time, Appendix E). R also described the emotional burden over time. She saw the burden moving from the person with dementia to the caregiver as the disease progressed.

It was hard for him (her husband), especially, for a man who was the .... You see it was hard for us (caregivers), but it's hard for them, in the beginning, once they get to the point they really don't realize that much. Then it's harder for us because they are getting worse and you know the pain and the burden is on us more. But while they are getting worse they are losing more memory so they can't really rationalize. But at first it is difficult for them. [The brackets and italics are mine.] (Session 4)

The roller coaster of swinging feelings while caregiving came up often in the group. L described it in the following passage.

L. "I've yelled at him, and I've slapped him across the back, and said I can't stand this and blah, blah, blah, Then I felt sorry that I ... The only thing he ever said to me, snapping back, he said, 'What makes you think you're so perfect?'"

(laughter)

R. "They don't know what they are doing."

L. "'What makes you think you're so perfect?' I said 'Well I'm doing better than you are.'"
K. “So what was it about when you said ‘Then I feel bad after I’ve yelled?’”

L. “Well yah, I feel kind of guilty. Sometimes I didn’t feel so guilty, I thought ‘Oh I’m so sick of him carrying on like this.’ I thought, ... Well he went into respite too for some time, I thought, ‘I can hardly wait to get him out of the house!’ Which I felt like. And in a way it is a relief. It is a relief.” (Session 4)

Resentment was defined as one emotion felt by the participants. L described two kinds of resentment. She felt resentful that her husband did not have the insight to see how much she was doing and how tired she was. She also felt resentful that the weight of heavy decisions fell on her shoulders. An example of this was when she had to decide to sign a Do Not Resuscitate medical form at the care facility for her husband. She specified though, that she did not feel resentful that the dementia had happened to her husband. She felt it more when not receiving recognition, not about having the disease in the family (session 4).

F also described feelings of resentment about several issues. These included going to visit her mother, how her mother treats her and how her sister relates to the family. She wrote:

I know I don’t always visit willingly. I resent my sister not visiting. I resent that because I am labelled the ‘softie’, I get dumped on. My mother knows what buttons to push to get me riled up. She once phoned me at 9:30pm to say the furniture was changed. I immediately thought my sister had removed the few pieces she has with her, when I got there nothing was taken and my mother just said, “Well, now you are here, stay a while and let’s talk.” It was then I finally saw the manipulation. Her friends tell me what a good daughter I am. The staff says the same thing. I just feel used.” (F, A Moment in Time, Appendix E)

Anger was also expressed as part of caregiving. F asked if other group members felt anger that 1) the person with dementia left things in a mess before they were moved to a care home, and that 2) the responsibility of making the decisions fell on the caregiver? Anger was a common experience for the participants. F wrote in
her narrative that she felt anger about caring for her mother. V said she got very angry that her husband left her to deal with everything. L said she would lose her temper and scream at her husband when he lived at home. “Just stop repeating yourself, or stop wandering, or stop doing THAT.” The others agreed. There was a sense of abandonment and extra responsibility which lead to the feelings of anger (Session 2).

Similarly, frustration was part of the caregiving process. During the discussion in session 4, L described a situation that is indicative of the type of frustration felt by the participants. My interpretation is that she was feeling fear underneath, but the frustration came to the surface first.

L. “I lost him in Toronto at the airport. He went into the men’s room, and I was watching, but I guess, I, somehow I missed him, and I was in the waiting area, and the men’s room was just there, and I thought, I was just watching, and he must have slipped out. I was waiting and waiting, and then they began to call the plane, our numbers to get on the plane? (R. Oh, no.) Well I was frantic, I mean this is not the same thing as had happened so many times, and so I started to go and look, up and down, and one of the girls came along, you know, with one of the carts that arrive with the baggage, and I guess I must have looked absolutely desperate. She said ‘Is there something wrong with you?’ And I said, first I had gone to the counter and told the girl, what happened and she said could she announce his name? But he wouldn’t be aware of his name you see? I had him called in Safeway, and he never heard me. And so they called his name anyways. She said ‘Well you’re never going to get through the airport on foot,’ she said, ‘hop on and we’ll go looking for him.’ So she drove all over, and she had security men go in the men’s bathrooms, and then we turned back and went back to go, as you enter and go through security, and she turned down a long sort of corridor, and we went down there, and there he is sitting all by himself, hands folded. Now how he got down
there! and I said, 'There's my husband,' and she said 'Mr. L.' And he looked up and said, 'Oh isn't this nice, getting picked up.' Well, I thought ...

R. “I know the frustration. It's ...”

L. “Oh, Well, I thought, Oh, thank god I found him, keep your mouth shut, you know. I thought, oh my god, B! We just got on the plane, I'm telling, you, so I thought ‘Don't carry on, be glad you've got him.’”

K. “On the one hand you wanted to take a strip off him, and on the other hand...”

L. “Hit him over the head! I was just nearly, I was shaking, I was near tears, I was trying to hold back the tears ...”

R. “Yah, its those moments you, ...” (laughs)

L. “You just about go nuts.”

R. “You just want to throw your hands up in the air, and give up on the whole thing, ...” (Session 4)

In her narrative R also wrote about the frustration she felt when her husband was living at home. “Being an independent person, he wanted to manage things himself. ... We got into struggles. This caused me a lot of frustration. He wanted to be in control, but he wasn't capable of doing it anymore.” (R, Caregiver at Heart, Appendix E)

V was also aware of feeling frustrated. When telling the group members about her feelings she consciously re-framed her feelings of depression to feelings of frustration. She made a choice about her emotions and refused to be sad (Session 1).

Guilt was a feeling that dominated for the first few sessions of the group. R introduced the research group to the idea that there are two kinds of guilt. She encouraged the other participants to ask themselves if the source of the guilt was “real” or if it was “false”. Real guilt was over a situation that a caregiver could do something to alleviate. False guilt was a feeling about something that is out of the caregiver's control.
All the participants had felt some guilt. R however did not feel the emotion much any more. She had done the best she could at all time, so her remaining feelings of guilt were "false guilt". Her feelings were not grounded in the need for her to do something better. She felt she was human and did the best she could. R asked F if the guilt she felt during the group came from herself or from her mother. F considered this and wasn't sure of its source. Although F suspected it was more from herself, she said her mother was "never pleased". So who’s expectation caused the guilt? After examining her family relationships the guilt seems to be a package which F accepts from her mother when her mother criticizes and berates her (Session 2). F wrote about this later in her narrative (F, A Moment in Time, Appendix E).

In general, there were two times when guilt seemed to surface. The participants often expressed feelings of guilt connected to moving the person with dementia into a care home. Guilty feelings also came up when the caregiver had negative feelings towards the person with dementia.

Grief and loss were also very prevalent in the emotional experience of the caregivers. The experiences of grief and loss could be separated into four sections. Participants expressed grief and loss in the areas of emotional companionship, physical separation, anticipation of further loss, and bereavement. During the group, R put the experience of grief into a nutshell. “First we grieve the husband we lost, then we grieve the person we cared for.” (R, Session 3)

A large part of the grief expressed in the group was the loss of companionship due to the mental incapacity of the person with dementia. V was the participant who spoke about this the most. Her husband was still alive, but he was not there for her anymore. V felt guilty (having moved him to a care facility) and missed his company. She missed holding hands as they slept. She missed asking his advice on things (Session 1). When V read her story, she again spoke about the emotional loss, and her long history with her husband. She had come to some level of acceptance, but there was still a sense of grief and loss for her (Session 3).

The pain of being physically separated after the family member went into a care facility was intense, especially for the wives in the group. Having just gone through the
separation recently, L spoke the most often about this type of loss. In her narrative she wrote “We have been married 58 years. I feel empty inside. Perhaps his memory being less sharp is a blessing. He is not thinking about things the way I do. I am thankful he is still here.” (L., An Unexpected Sadness, Appendix E)

A passage from R’s narrative echoed this pain. It also made the point that she needed space to start to grieve.

A bed opened up for him in a care place. I had him admitted for the first time. It was a devastating experience. I felt that someone had pulled the arms off my body. It was terrible. The separation was terrible. And the feeling of hopelessness, knowing that he would not be coming back. ...After he went into the care place I began to grieve the experience. When you are so busy, you don’t have time to grieve. Now I had time again. It was very hard getting used to being in a house all alone. (R, Caregiver at Heart, Appendix E)

At another point in the group, L and R discussed the difficulty of living alone in the house after their husbands moved out:

K. “One of the lines I remember from your story was how hard it was to get used to coming home to an empty house.”

L. “Its horrible. God, (R. Yes, its really bad. I dreaded it.). I leave the lights on ... till I go to bed now. It’s not quite so bad as it was but coming home to that house. I thought I’d go nuts.”

R. “What about eating alone? ... I stopped eating there for a while.” (she laughs).

L. “Well, I, its not so bad now, (but) not long ago I jumped into my son’s car. I think I told you that. I said, ‘Can you take me home with you?’ ‘He said how are you going to get back?’ He lives out in Coquitlam. I said ‘Oh, you wouldn’t drive me back would you?’ He said ‘Well I’ve got some studying to do mother.’ He said, ‘Oh hop in.’ So we started. I thought ‘Oh poor guy, he’s really, his mother is really pressuring him.’ But oh my god, I couldn’t stand it.”

R. “We need people at times.” (Session 4)
Another issue of grief and loss which the group discussed centred around the emotional difficulty of dealing with the family member "dying inch by inch." The dementia caused changes for the worse on a continual basis. This meant continual pain to the caregivers. It was a combination of the losses at present and with the awareness that more losses were to come. This was the participant's definition of the concept of anticipatory grief. They felt this type of loss fit their experiences (session 2).

Bereavement was the final type of grief expressed in the group. Dealing with her feelings of bereavement were R's purpose for coming to the research group. She was the only participant who had gone through the death of the person for whom she was caring. The insights that follow were all from her narrative in the group.

"After he died, I was thrown into a different kind of grief; where there was no caring, or loving the person, or being needed. The most difficult year of my life started. It was very painful." (R, A Caregiver at Heart, appendix E) The great feelings of loss centred around the fact that her husband was really gone (both physically and mentally) forever, and that her life would never be the same again. She didn't cry for months, because she was emotionally "numb." She wanted to continue the unfinished grieving process so that she could "get on with her life." Her description of life after her husband's death was of "building a new building from scratch, but with the previous cornerstone missing." She had been married to her husband for 50 years (session 1).

She described a ritual which she created to help her with her grief:

In 1950, when we got married we used to laugh about seeing the year 2000. It seemed like 1000 years away. When the year 2000 arrived, I was there with the whole family. I said "It is the year 2000. We made it to the year." He seemed to understand. However after 18 days, on January 18th, he passed away, so we didn't make the day of our 50th Anniversary. The day that our 50th Anniversary would have been, I went to the grave-site. I placed a red rose on his grave. I thanked God for a marriage that lasted a lifetime. (R, Caregiver at Heart, appendix E)
Eventually, R wrote about coming through the darkness of grief and moving into a new time of her life:

I went through the stages of grief in a grief sharing group which was a great help to me and my recovery. A Bible verse kept coming to mind ‘Weeping may enter for the night, but joy cometh in the morning.’ Now life and joy has started to come back to my life. I am engaged to be married again. (R, Caregiver at Heart, appendix E)

Overall, the third theme of caregiver health was a significant part of the participant's experience. They felt strain and negative emotions while charting the waters of being a caregiver. This theme is significant to the research question in that it has a direct impact on the attributions the caregivers make about the positive or negative impact of being a caregiver. Feeling grief and loss, anger, or guilt impacted the caregivers' self esteem. It was also hard for the caregivers to see the positive side of life when they were physically and emotionally exhausted by the demands of caregiving. The positive emotions felt by the participants are explored in the benefits section of theme four.

Theme Four: Shaping caregiving in the research group.

The fourth theme to be explored encompassed several issues which were developed during the research group. These issues included the benefits of caregiving, the meaning of self care, and different types of meaning in the caregiving experience. The participants felt that these issues were important to pass on to other caregivers. They also had a strong influence on adding to the positive aspects of the caregivers' lives.

Benefits of caregiving: There were some moments of joy in the narratives in the group. These were the benefits of caregiving. The caregiving experience was still a relationship with a person whom the participants loved.

One of these benefits was the feeling of being needed. It motivated the caregivers to continue going to the care facility daily to bath, feed, or play with their family member. The dependence from the period of caring at home was not
Collective Narrative with Caregivers

completely gone. R wrote “The caregiving ended when he died. Up until that point I would bath him. I felt needed.” (R, Caregiver at Heart, Appendix E) In a similar vein, V wrote

He knows me yet and depends on me. There is very little communication on his part, but I go 3-4 times a week and chatter away to him, take him for walks, dinners, join him when I can in the activities at the care home. We play a card game he enjoys. He is happy in his own world. (V, The Two of Us, Appendix E).

A second benefit, mentioned in particular by F, is the perception within herself, and from society at large that she is a good human being (Interview, May 1, 2001). “Her friends tell me what a good daughter I am. The staff says the same thing.” (F, A Moment in Time, Appendix E)

A third reason the participants continued to care, and found some enjoyment in the experience was due to the activities which they could still do with their family member. “The good ones (days) include my singing with my mother, taking her to the opera, taking her to sing-alongs, taking her to visit friends for lunch, taking her for walks and making sure she is entertained.” (F, A Moment in Time, Appendix E).

Similarly, R wrote,

I was able to spend quality time with my husband. I would take him to the roof terrace of the care home. We watched the sunset over the Northshore mountains and the birds returning from the sea. I used to pray with him and sang his favourite hymns. It was a great blessing to him. Those were the precious moments of caregiving. (R, Caregiver at Heart, Appendix E)

**Self care:** One of my assumptions about caregiving is that the caregiver is just as important as the care receiver and therefore should take care of themselves. This idea was borne out by the perceptions of the participants. R spoke at length about how, in hindsight, she felt she did too much work as a caregiver and how she would change her caregiving style.

If I had to do it again (God forbid), I would let more things go. I think I was emotional and I thought I had to do this or that. I would be easier on myself. …
would not make some things so important. ... At the time I felt it was necessary and I did it. Now I think I would do some things differently. (March 8, 2001)

During the first period of caregiving at home and the following separation, it may be that self care meant keeping the family member with the caregiver as long as possible. This was the longing, so this became the goal of self care. Once this had passed, the focus moved to other types of self care. The participants spoke of making a decision to care more for themselves. This self care then took such forms as getting exercise, "getting rid of the extra (emotional) baggage" (R, session 4), and "just do(ing) nice things, enjoyable things if I could" (L, Session 4).

Self care also included changing caregiver patterns. Besides the philosophical value of life and love, the meaning for R of caregiving was to be self-sacrificing, perfect, and responsible. This was a pattern she had before her husband's illness. She called this old pattern "excessive caregiving." She expanded on the topic below:

R. "There are things that I would change. I mean, to change the excessive caregiving once I'm there. I only see it now. One of them was when he was still going to work and all that. Like I was always up and making breakfast and that's fine, I'm not saying, and seeing him out the door, but um I did it also when I was sick. Now I would say, 'Listen I'm sick you make your own breakfast.' You know, I would not do it anymore. But somehow, I managed to get up and make his breakfast, sick or not sick. ... And there are different things like that. Now looking back, I think well, 'Why did I do it?' That was excessive caregiving, that was unnecessary."

K. "So what was your answer. Why did I do it?"

R. "Yes, I answer, why did I do it? Is it just because I'm so used to just caring that I don't know how to stop even when I'm sick. It might be something deeper. I don't know."

K. "That its OK for other people to be sick and go to bed but it's not somehow OK for you. You somehow still needed to take care of everything and make sure everything was running. That was an
expectation you had?"

R. "Yes, I have a very organized mind and that's one of my weaknesses, that um that I try to be perfect. But nobody can be perfect, you know there is no such thing as perfect this perfect person. I discovered somewhere along the line, and every since I have been trying to bring it down, you know I don't have to be, I can let some things go, you know,"

L. "Well you better let this new husband bring you coffee."

(laughter)
L. "Start right away!"
R. "There's an idea."
L. "Don't get up the first morning. Just stay in bed."
R. "I get up early in the morning. I don't mind getting up, and I like to get up. But when you're sick you should be able to stay there. Not that my husband ever demanded or anything. It was me! I was foolish enough to get up. That sense of responsibility somehow was always there. ..." (Session 4).

F was the other participant that spoke directly of making changes in the way she lived out her caregiving. In her narrative, F expressed a wish and made a move to change her family roles. This change pertained particularly to being a caregiver.

I'm resentful my sister doesn't share the burden, and yet, I'm glad she doesn't as then I can play the role of the martyr. I am not comfortable as a martyr. As I get older I prefer not to be the victim. As a caregiver, I have set limits and learned to treat myself so I don't get pulled down to a level of ill health. In order to survive, I have to consciously resist the wave of helplessness and depression brought on by being exhausted, frustrated, tired, and self-recriminating. (F, A Moment in Time, Appendix E)

In the months following the support group she implemented some of those changes. In the group and in her narrative, F described feelings of guilt and anger towards her mother and the situation she was in. She mentioned in the final interview, however, that she felt less guilty now that she had been through the support group.
She could, for example, deal with her mother's daily phone calls "more constructively." Her mother called several times a day. At the follow-up interview, when F was busy she told her mother that she would call back later without feeling guilty. She also described several coping strategies she had begun to use when relating to her mother to minimize the tears and bring more laughter into their relationship. For example, she began using more humour in her conversations (Interview, May 1, 2001).

Meaning in caregiving: When asked the direct question of what meaning caregiving had for them, the participants each had a their own response.

For F, there were three main ways she felt it created meaning for her. First, caregiving was part of defining her ongoing relationship to her mother. Her sister had cut off from the family and therefore did not have the benefits of knowing her mother in the present. Knowing her mother in her later days was something F found meaningful. Secondly, it gave her a sense of personal worth. The sentence "I am not a bad person" was significant in expressing the meaning caregiving gave to her. Thirdly, the meaning of caregiving was encompassed by moment-to-moment responsibility for another person. She indicated it was more that looking after children, who grow more independent with time. This type of responsibility increased with time (Interview, May 1, 2001).

The meaning in caregiving for R was also many sided. She cared because she valued human life. She cared because of her long term relationship with her husband, and because it is a familiar role for her. She said "My goal was to care for him as well as it was possible." (R, Caregiver at Heart, Appendix E)

L and V both put the meaning of caregiving in the context of an ongoing loving relationship. As V wrote in her narrative, "You give all you can and get nothing in return, but you do it cheerfully because of love." (V, The Two of Us, Appendix E).

There were several other meanings which the participants touched on in relationship to caring for a person with dementia. These included coming to terms with the disease, deciding to be a caregiver, the changing meaning of communication, and the insight gained from experience.
Attributing meaning to the experience of having a person with dementia in the family was part of coming to terms with the disease. The participants went through a process of adapting to caregiving, accepting the disease and moving on with their lives. They found hope in their other family relationships and in developing new friendships. Several of them justified the difficulty of dementia, by remembering that other people had worse experiences than they did (Session 4). They did however, admit that caring for a person with dementia was hard to take. It was generally felt that a physical disease might be easier to accept, because it did not mean the loss of their family member’s mental capacity (Session 3).

The decision to care was also part of making meaning of the caregiver’s experience. There were two answers in the group about the moment of deciding to be a caregiver. For L and V there wasn’t really a moment of conscious decision. L said, “I don’t think I really thought about it. You wanted to be there, and you wanted to look after him. That’s all you think about. Not what it will entail.” (Session 4) For the other two, it was a more specific moment than that. The moment arrived for F when her mother asked her not to leave. F realized this was a chance to gain her mother’s approval and respect. That was her moment of deciding to be a caregiver. For R it was a mixture of beliefs and relationship.

Well I always believed in taking care of people, in taking care of the sick, and I was here on Oak street and we had placards. And I chose the one, Choose Life. I was holding it up, because not only for the unborn but I felt that the elderly, that there’s euthanasia creeping in, and aided suicide, is out there, I thought Choose Life, choose life whatever situation it is Choose Life. ...And I always believed in life and in taking care of people until they died. ...You’re there, its your husband, you love him, you want the best for him, and you start to taking care. It comes really naturally that caregiving. ...You just do it. (Session 4)

A further aspect of making meaning for the caregivers was the issue of interpersonal communication. The type of communication between the caregiver and the family member changed due to the dementia. The loss of short-term memory often
meant that the caregiver heard the same sentence or question again and again. The conversations became one sided. As this happened the measure of a meaningful communication changed for the caregivers. The caregivers took meaning from spending time with the person with dementia. L said, "He always tells me he loves me. ... And he always says thank you for coming. So in that way I guess its more, personal. Its nice when he says that." (Session 4)

R shared how her son took meaning from the activities he and his father used to do together.

I remember one day, my husband was outside. My son was already doing the job, but my husband took the rake and he was there and he didn't really rake that long. Maybe 10-15 min. at the most. ... Just this fall my son remembered, 'Mother I remember when Dad and I used to rake the leaves together.' It gave him a good memory. He (my husband) was already sick at that point, but he didn't even mention that. It was just "Do you remember when father was raking the leaves with me?" (session 5)

As mentioned above, communication between F and her mother remained conflicted. She described it as follows:

I think it would be a lot easier for me if she was more ill or incapacitated, but then I feel guilty for having such thoughts. I enjoy our outings until she starts in on her negative comments, which just make me exasperated and frustrated. I become defensive and fire back at her that she created the situation she is in by not agreeing to have live-in help, or not getting an automatic wash machine, etc. She is so stubborn and bossy and then I realize it is her illness. I try to use all the techniques recommended in the book. 'Mother, I will phone you when I can. Please don't have the staff dial me." I have tried to set a schedule for phone calls and visits. Unfortunately, my own schedule is loose and sometimes I cannot be regular. I do my best. ... I think my mother has compromised somewhat as she expressed her gratefulness at my taking her out for a drive to listen to opera, for example. At times she shows insight and at others, she is totally selfish and self-centered. Her general physical health
is improving. Her short and long-term memory is excellent. She has regained her sense of humour. She is learning new songs and she knows the names of all the staff. (F, A Moment in Time, Appendix E)

V also talked about the change in physical and emotional communication. She wrote:

I miss the communication we had. To talk about things that mean something only to we two. I bring him home periodically. The last time he was home, he went to bed easily. When I crawled in I snuggled up to him and wrapped my feet around his. There was no response (I'm not talking about sex). I asked him to turn over and snuggle me up. I needed to be hugged. His arms fell listlessly over me. I miss him so. He does still tell me constantly he loves me. I cherish this even though the physical snuggling is not there. (V, The Two of Us, Appendix E)

A final meaning of caregiving for the participants was the insight it gave them into the pain and difficulty that others experience (session 4). This was seen as one of the benefits of a support group with others who have been through similar things (Session 2). The ability to understand and adjust to life's situations was attributed to time and to human nature.

R. "There is something about human nature. We do get used to it."
L. "Yah, that's good, and time. Time helps." (Session 4)

In summary, the caregivers chose to expand on three ideas in the research group which shaped their sense of self and the meaning of caregiving. The benefits of caregiving included the continued relationship and the significant personal moments. Defining self care was also valuable to the caregivers. Valuing self care meant the caregivers wanted to make more choices for their immediate personal benefit. Finally, outlining meaning in caregiving addressed some of the caregivers' philosophical insights about their experiences.
Theme Five: The research experience

The final theme which emerged as part of the results was the impact of the research experience. This theme described how the participants felt about the research group and writing the narratives as a method to explore their lives as caregivers. Writing the narratives was the first idea discussed. This was followed by the impact of the support group experience. The challenges and benefits of this approach were outlined as follows:

Writing the narratives: The experience of writing the narratives was seen as positive by all of the participants. After some initial trepidation about writing, they were interested in the act of story-telling. Several of the caregivers reported feelings of catharsis, wholeness and closure as a result of writing and sharing the individual stories. R saw it as good therapeutic activity. She said

I felt really good about it. The whole day, I thought, something good (sic) to me, happened today, it was very therapeutic, of course I wrote the story, that was great, and I know now my thoughts were very scattered. But that’s OK too, and I don’t know, I just felt really good about it. Like some kind of a wholeness that I can’t explain, and I thought, Why didn’t I do this before? Why didn’t I keep a journal? That would have probably been it. And um, so, I just felt great. (...) But it helped me. Some kind of a closure too, I think, I was able to see it, all those years, and now I can see the light. The caregiving is over. Or maybe its starting, who knows, (laughs) but that’s life. ...That phase is over. (Session 5)

Writing and sharing her narrative in the group helped L come to terms with her decision to move her husband into the care home. She came to see that it was best for her health, and that in the circumstances she did not have any other choice (Session 5). V enjoyed reading her narrative to the group. She said writing had been a bit challenging, but she was glad to contribute her experience to the project (Session 3).

Writing the story also brought a catharsis of feelings and clarity of the situation for F. “Putting it down on paper made me aware of things I may have known at some level, but was not really aware of before.” It brought some new insights to the surface.
The one she particularly focused on was her familial role to her mother. She realized that she was still in the child role, and responding to her mother as a child. She had thought previously that the tables had turned. Because she was not so responsible for her mother's affairs, she thought of herself as parenting her parent. Emotionally, however, through her narrative it became clear to her that she was still responding like the child. She mentioned how she let her mother push her emotional buttons and control her time. She felt bitterness about being forced to be a caregiver. The disease happened and she did not feel she had a choice. Finally, writing her narrative made her more aware of the positive aspects of her relationship to her mother. She indicated that she was focusing more on the positive part of the relationship than she had before.

The support group experience: As the members were leaving session 1, they expressed their appreciation of the group and the time to talk. This feeling of emotional support and connection continued throughout the sessions. V said “It was hard to get people together, but it was helpful to talk and hear the other’s stories.” (Session 5) R felt that the group was too short and that she was very fond of the other women (Interview, March 8, 2001). She also said “In a support group you realize you are not alone.” (Session 2) There was a belief among the participants that support from connection with other caregivers was important to living and coping with the experience of caring for someone with dementia (Session 5). F thought the strength of the group was to normalize the pressured, angry, or exhausted feelings as being a natural response to the situation.

Sharing the narratives was a risk for all the participants. F felt the reading made her more vulnerable. She felt that this touched on one of the drawbacks to the group in general. Sometimes when we were giving feedback, she felt the attention was focused away from the experience of the author towards the experience of the person giving feedback. By trying to say “I had that experience too,” the person giving feedback took the spotlight away from the author. The biggest risk for her was of sounding selfish in her choices and feelings (Interview, May 1, 2001).
In summary, although reading the narrative in the group was perceived as a risk, proper facilitation of the group would create the validation and safety necessary to make the research experience useful. The benefits of writing the narratives were to bring a sense of accomplishment, an emotional sense of wholeness and catharsis, new insights and validation of the caregiver's experiences. These outcomes were helpful to making personal meaning of the caregiving experience and shaped how the caregivers defined themselves as people.

Reflections on the Research Process

As a final contribution to the results chapter, the following section were my personal reflections about the processes of researching and completing this thesis project. These insights describe how the group and narrative process shaped my meaning and definition of myself as a professional caregiver.

Parallels in my caregiving experience.

There were parallels between my experience as a professional caregiver (a counsellor) and the research participant's experience as caregivers to their family member. Like the participants of the research group, through studying caregiving, I was clearing the way to move forward in my life. I learned from them who I am as a caregiver, and how I can use this energy in my professional practice. In the past few years, I have also learned where I have to watch that my choices are for the client's benefit, and that I am not overly responsible for the client. My definition of overly responsible is to try to direct the decisions of my clients, or to get too emotionally involved (so that the client becomes dependent on me for too long, or that I cannot ground myself emotionally and lose my ability for self care). I realize that I designed the group to include things I myself would like to receive as a caregiver; a chance to share my story in a group and be validated for my sacrifices. I believe that going through a creative process around an experience can put expectations and choices into perspective. Before I asked the participants what meaning and sense of self they get from their experience, I went for personal supervision to answer these questions for myself. I clarified my personal assumptions and my intentions for the group. As a
researcher I can initially ask the participants what I am personally interested in hearing. Then, the research questions were lead by the interests of the participants in the group (Journal 5, March 19, 2001).

A defining difference between the group members and myself, was that, although I was employed as a respite worker with people who have dementia, I have never been a primary caregiver for a chronically ill family member. This was significant to the findings and the caregiving process. I view caring for a family member at home as a more intense experience than my own personal career as a caregiver (Journal 5, March 19, 2001).
Chapter Five: Discussion

The research process of meeting, writing, discussing and analyzing was a journey of gathering rich experiences. The next question is how do all these themes, experiences, and results fit into the context of the academic findings at large? This chapter will put the findings of this study into place in the larger fields of both caregiver research and narrative methodology. It will also address the success and the limits of this study. Based on these, future research possibilities will be discussed. Given the rich self-analysis of the participants, the broad findings in the results, and the positive impression left by the narrative group experience, this study indicates that the use of a collective narrative approach to caregiver research and therapy is dynamic and useful.

Caregiving Research Connections

When reviewing the findings and matching the pictures, many of the findings of this study fall into line with previous findings about the experience of primary caregiving for a family member with dementia. A few of the concepts within the themes, however, were not evident in previous research.

Physical and emotional strain.

All the participants saw caregiving as a strain, both emotionally and physically. Under the section Caregiver health, the participants noted instances of stress-related illness similar to those found in such studies as Lieberman and Fisher (1995) and Mui & Marrow-Howell, (1993). Two of the participants here reported physical illness attributed to stress, and emotional distress was well documented in the sections on emotional experiences of caregiving, depression and loss of energy.

Contrary to the participant’s attributions in this study, in their review of the literature, Schulz, O’Brian, Bookwater, Fleissner (1995), did not attribute significant quantitative outcomes to the relationship between physical illness and caregiving. The correlation was not seen as high enough to be causal. Mui, and Marrow-Howel (1993) however, expanded the debate and found that there was less physical effect on daughter caregivers and more physical impact on the health of spouses. These
findings do not match our study, however, in that the one daughter caregiver, F, did attribute heart problems to the stress of ongoing caregiving. She also felt burdened by the care of her mother which contributed to her physical distress. In Braithwaite's 1996 study on burden of caregiving, she found increased levels of burden in the caregiver when the person with dementia had severe degeneration, there was role conflict in the relationship, enmeshment, and unwillingness to care. In Braithwaite's study burden is described as a frustration of basic needs. This description could be used to describe the family dynamics which F described. She has ambiguous feelings about caring for her mother. F may be one of the fewer younger caregivers to experience physical symptoms due to the stress of her situation. The meaning she attributes to being a caregiver has an effect on her feelings of burden which in turn may lead to heart problems. It may be symbolic sentimentality, but it is interesting that she experienced heart problems as a result of her conflicting feelings about caregiving for her mother. Irrespective of her family dynamics, F's experience certainly supports the findings from Pavalko and Woodbury's (2000) recent study where they found emotional distress in mid-life caregivers increased while caregiving.

The caregiver literature is more comfortable claiming a general but significant emotional effect for all caregivers (Walker, Pratt & Eddy, 1995). This emotional effect is also clearly evident for the participants of this study in the section of emotional experiences in caregiving. These included negative feelings of resentment, anger, frustration, guilt, grief, and on a more positive note, relief, joy, and gratefulness when travelling the caregiving road.

Another example of caregiver strain is depression. One of the members of this research group was being treated with anti-depressant medication. She attributed these feelings to the recent separation she and her husband experienced when he moved into a care facility. Similarly, Schulz, O'Brien, Bookwala, and Fleissner (1995) found increases in anxiety and depression in caregivers and attributed these to the overall life situation of the caregiver. The life situation included negative behaviour in the caregiving dyad, financial change, life satisfaction, and the perceived health of the caregiver. Other authors also cited depression as an outcome when the severity of the
memory impairment and the behaviour problems of the family member increased (Majerowitz, 1995; Li, Seltzer, and Greenberg, 1997). Significant changes in life situation and behaviour difficulties with her husband were part of the situation faced by the spouse in this study. The depression was part of her response to the loneliness and loss she felt. It annoyed her, but it forced her to take a period of reflection and adjustment.

Stress and burden.

Other themes from the results chapter point to the way that stress impacts the caregiving experience. This finding is supported by previous research. The difficulty of diagnosis and placement in a care facility are cited as part of the ongoing emotional stress of caregiving by Chenoweth and Spense, (1986). These authors also wrote that stress varies by the phase of caregiving (Chenoweth and Spense, 1986). This was borne out by the participant's perception of stress in this study. Each of the women was in a different phase of caregiving during the research group and found their level of stress changed with the changing situation. Role overload (having to do too much) is described by Mui & Marrow-Howell in their 1996 study as an important negative influence on caregivers. According to Pavalko and Woodbury (2000) the physical limitations of the caregivers eventually lead to the placement of the family member in a care facility. This fit with the experience of our participants. For them, the physical limitations took the form of difficulty with lifting their family member, loss of personal energy, and difficulty coping with the non-stop demands of caregiving. As Walker, Pratt and Eddy (1995) remind us, "In fact, many factors, including poverty, role, conflict, excessive demands, lack of caregiving assistance, onerous caregiving tasks, and the loss of a meaningful relationship with an impaired loved one, can contribute to negative outcomes among caregivers." (p.408). Acknowledging role overload and physical limitations as meaningful guidelines in caregiving may prevent some negative outcomes.
Benefits.

Caregiving also had benefits to the caregiver. The participants enjoyed some of the activities which had personal meaning to the family member (this was particularly the case after the family member lived in a care facility). The caregivers also valued feeling needed. F made a moral judgment of herself as a good person because of her caregiving career. Similar emotional rewards were reviewed by Walker, Pratt and Eddy in their 1995 overview of caregiving. These rewards were naturally very important to the caregivers as a sign of the ongoing relationship to their family member and a way to motivate continuing in a caregiving role. As important as the benefits are to the caregivers, the findings indicate that the burdens or negative side of dealing with dementia outweigh the benefits.

Social support.

Our findings supported the literature on the impact of social support on caregiving. Once the participants tapped into professional support, such as respite care or counselling, they felt it was most helpful when both the informal and the formal caregivers viewed the provision of care as a partnership. This partnership was also proposed by Walker, Pratt and Eddy (1995) as the most beneficial form of long term care.

As was discussed in this study and in the literature, this partnership was not always evident. Sometimes, as in the cases of hurtful advice, social support was not helpful. Abel, in her 1989 study of adult daughter caregivers also found that the women's experience of social support was not always positive. Some well-meaning friends tried to help by downplaying or trivializing the experience of caregiving. Both for the daughters in Abel's study and for the caregivers in this one, such feedback was seen as dismissive and invalidating.

In general, however, social support does buffer the caregiver from stress. It was seen as invaluable to continuing as a caregiver. Li, Selzer, and Greenberg (1997) outlined three types of social support which were found to be helpful to caregivers. These types of support were weighted differently by spouse and daughter caregivers.
Social participation (either being present at home, or going out to activities) was beneficial particularly to the daughter caregivers in their study. Emotional support was most valued by the wives, and physical caregiving support was also seen as helpful. This bears itself out in the findings of our group as well. Although caregiving support was not offered as part of the research, the participants saw emotional and social connection as being very important to them throughout their caregiving experience.

Finally, in relation to social support, three of the participants in this study mentioned the role of religious belief as an important resource. This supports the findings of Chang, Noonan, and Tennstedt (1998). These authors noted that a strong religious and/or spiritual affiliation had an indirect positive influence on the quality of the caregivers relationship to their family member. It also seemed to decrease the instance of depression and the role submission of the caregivers. From the findings of this study, religious belief created a natural buffer between the family members, in that it ensured an ongoing external priority (relating to the spiritual) and a perceived source of energy and strength.

**Changing roles.**

Changing roles within the family was another theme from the research group which is supported by the caregiving literature. In the experience of the research group, accepting that the roles were changing and finding meaningful ways to continue to relate to their spouse or parent was important to caregiver well-being. Majerowitz (1995) also found that the ability of caregivers to adapt had a significant effect in lowering the instances of depression. As R indicated “You get used to it.” (session four).

The participant’s changing roles were influenced by their perceptions of the past relationship. As Lewis says, when discussing the impact of the previous (marital) relationship on present caregiving, “The way people use the past affects their current perception and experience of caregiving.” (Lewis, 1998, p. 229) This played itself out in several ways in the research group. F became aware that she had not significantly changed her role to her mother. She attributed relationship conflict to long standing
patterns from their pre-illness relationship. Also for the three wives in the group, previous relationship patterns influenced the present caregiving relationship. Perception of who was the dominant person in the pre-illness relationship influenced changes in present caregiving. R was the dominant one, and although she loved her husband, she eventually saw her caregiving as part of the marriage contract. L said she had an equal relationship with her husband and was feeling the loss and pressure of caregiving alone. V still felt a strong emotional bond, and although she felt her husband had been the driving force in the marriage, she was learning to take over that role as part of her caring. These motivations were also found in Lewis's study (1998). Previous family relationships, which involved previous roles as a caregiver, also lent an air of familiarity to the spouse's present perceptions of care.

Putting life in limbo.

There were several points of intersection between the theme of putting a personal life on hold and the literature on caregiving. Gradually having to take responsibility for the family and the household had an impact on the caregivers lifestyle. This included gaining new skills, which would possibly imply an increased sense of mastery (perceived control of life) for the caregivers. As Skaff, Pearlin, and Mullan found in their 1996 study, however, the participants in this group felt a loss of control when caring at home. In the Skaff et. al.'s study, mastery did not increase until after the family member had died. For two of the caregivers in this study feelings of personal control began to return slightly earlier; about a year after their husbands were moved to a facility. The other two caregivers were still struggling with independence and mastery. Role overload, as mentioned above, in the section on caregiver stress, was part of this lack of personal control and space (Mui & Marrow-Howell, 1993). Abel (1989) found that caregivers submerged their own needs partially due to their awareness of the costs of caregiving and their resulting concern for the emotional well-being of those around them. This would, in turn, reinforce the perceptions of role overload. Increased feelings of mastery would mean that the caregivers feel they have more choices and options for action in their lives. This was the case for the caregivers
who experienced more personal space (both physical and emotional) after their family member had moved to a care facility.

**Social isolation.**

Social isolation was also a theme for the participants of this study. The constant nature of caring for a family member at home tended to mean that caregivers stayed at home. For the wives, their social networks changed. They had more single friends, and sometimes lost touch with long term friends. Some friends were not comfortable with the dementia and distanced themselves from the caregiver. This lead to the perception that there is a social stigma connected to dementia. For the caregiving daughter, some of her friends did not understand the involvement she felt with her mother and the burden of care. Similar experiences are described by Dillehay and Sandys (1990) as the loss of opportunities for social connection, and by Pearlin (1992) as the social isolation of caregiving.

**Grief and loss.**

Grief and loss were an underlying theme of the caregiver’s experience. All life transitions include some loss due to changes. This makes loss integral to the human experience. The research participants felt that caring for a family member with dementia is a situation with inherent loss. There is the loss of some personal freedom, the loss of energy and time for self growth, the loss of a meaningful relationship, and the loss of a previous lifestyle. Authors such as Harvey (1998), Walker, Pratt, & Eddy, (1995) and Reeves (1999) discuss loss in the context of aging and caregiving which confirm the findings of this study.

The idea of anticipatory loss (grieving for a loss that is yet to come, such as a death) also found resonance with the research members. This needs to be tempered with the understanding that there are real present losses which are part of the current changes (like the loss of meaningful two way conversation) which are separate from the anticipated death (Reeves, 1999). Reeves goes on to say that some grieving processes are "complicated by lowered self-esteem, shame, guilt, a sense of
powerlessness, or general ignorance (of grieving) in society." (Reeves, 1999, p.3) Such experiences were not uncommon among the group members.

New insights.

One theme not mentioned in the studies on caregiving is the theme of getting used to the sickness. The caregivers in the study said that they lost sight of how physically and medically sick their family member really had become. Being in constant contact with a person can mean that the caregiver didn't notice the small changes. This loss of perspective or perception was not related to the loss of caregiver self or identity. Awareness of this possibility could influence decision making, for both informal and formal caregivers, around continuing with the best type of care (be that at home or in a care facility).

Another theme noted by the research participants was the tension between providing protection for the person with dementia while still treating him or her with respect. This was seen as part of the physical process of caregiving. It was rationalized by the caregivers as an uncomfortable necessity. Actions that are respectful can change as the illness progresses. The caregivers felt conflict between keeping their family member safe and treating him or her with the respect usually due an adult in this society.

Meaning in Caregiving

The meaning of caregiving for the participants was tied into their relationship to their family member. It was integral to see the person with dementia as a human being while still acknowledging the practical realities of the disease. The caregivers found meaning in continued caring as an expression of an ongoing loving relationship. Lewis (1998) also found this in her study. Similarly, the motivation to care came from the importance of the long term relationship (who the family member had been in the past) and the present relationship (who the person is now). There was a sense of meaning from knowing the person towards the end of his or her life.
For some of the participants there was a moment of decision to care. This decision was a result of the past relationship, the philosophical value placed on human life, and the familiarity of past caregiving roles. For others there was no particular point when a decision was made. The role of caregiving seemed a natural extension of the situation. For all the participants, they took on the constant responsibility for another person without being fully aware of what it would entail. The driving force was to show love and do the best that was possible throughout the caregiving experience.

Some of the meaning of caregiving for the participants changed as the disease took its toll. The meaning of communication in the relationship shifted as the verbal and physical interactions became more one sided. Interesting personal conversation was replaced by finding value in the words “Thank you” or “I love you.” Spending time with the family member took on increased meaning.

The meaning of moving the family member into a care facility was also significant and changed with time. At first, the move meant a loss of independence for the family member and the end of the marriage for the wives. It was a very difficult change. Later, the move was perceived as allowing quality time with the family member. It also created more personal space for the caregivers, and a relatively safe environment for the family member. Lewis (1998) found that the meaning of separation due to institutionalization varied in relation to the interdependency of the couple and the emotional closeness of their relationship before the onset of the dementia. This was also true in this research group.

Showing and finding personal worth was another meaning found in caregiving. The act of looking after the family member bestowed worth on the person with an illness. It was also perceived as a source of worth by several of the participants. This helped the caregivers come to terms with the illness.

Although they felt a physical disability might have been easier to deal with, there was a tendency to downplay their situation by saying that other people had worse experiences. Dementia was not the worst thing that could happen to you. Their experience did increase their empathy for others. The participants saw this as the insight they gained from being a caregiver. This supports the findings of Bar-David
She reported that one of the benefits of caregiving is a heightened sense of altruism.

Perceptions of the value of the relationship was a motivating factor for caregiving. Particularly in the parentcare relationship in this study, there were subtle shades of the meaning of the relationship which changed the motivation. The meaning found in the mother-daughter relationships for daughter caregivers was studied by Sheehan and Donofio (1999). Their findings that the daughter caregivers felt a sense of personal sacrifice are consistent with the experience of the daughter caregiver in this study. She also felt a new redefinition of the relationship and a renewed value on the importance of her interaction with her mother. One difference when comparing the two situations is that for the daughter in this group she was not sacrificing as a means to repay the care and attention she had received as a child. She was sacrificing to answer a specific request that her mother made of her. In contrast, repayment of past love was a goal of the daughters in Sheehan and Donofio's study (1999).

It is interesting to consider the process which caregivers go through when making meaning of their experience. Perry and Olshansky (1996) reported that in the family they researched, the family members all went through a similar process of creating meaning for the caregiving experience. This has implications for the creation of a collective narrative in a support group. Is the process of creating meaning similar in the group as well as in a family, or is the similarity of approach indicative of a family pattern? Presumably if the group members discuss the meaning of caregiving and spend enough time together to create a group culture, then the process of meaning making may follow a common path when writing a collective narrative. This is to say that the group members influence each other in their perceptions. Disagreement among the members may change the meaning-making process of the individuals. The fact that the participants in this group were in different phases of caregiving did not seem to change the communal meaning they found in the experience. The one exception is the benefit of separation by institutionalization. L was still reeling from the separation and did not feel that it was a benefit. Conclusions of a communal meaning
do not address the idea that the caregivers followed a similar path in finding that meaning.

One part of the process was that the caregivers found it freeing to think of their caregiving career and the life of their family member from a longer term perspective. To see the disease as a small part of the life, and to keep the many years of relationship in mind were comforting. Efran and Clarfield (1993) also found that adapting a broader context allowed people to integrate and accept contradictory experiences. The contradiction for the caregivers was the pervasive quality of the dementia in relation to an ongoing meaning-filled relationship. DeVries, Birrin and Deutchman (1995) presented the viewpoint that writing a life review encouraged acceptance of the present situation by creating perspective. Meaning was found for the caregivers in putting their caregiving career in a long term context.

**Sense of Self: Individual and collective identity**

It is not the type of change ... "it is the meaning that the (change) holds for a person that will determine the process of adjustment." (Reeves, p.11) This meaning not only changes the process of adjustment, it also shapes the caregiver's sense of self and identity. The meaning written in the last section is the basis of how the participants perceive the experience of caregiving. It is this meaning on which their co-constructed sense of self is based.

The participants were in the process of constantly constructing their self-perception. Like multi-coloured strands of yarn which twist against each other, each person contributed to the co-construction of the colors in their fellow group members. Then on a collective scale, the yarn wove itself together into a pattern. Each person added to the co-construction of the group identity which is known as the collective narrative about caregiving. So, what were the results? What culture and ideology shaped our invention? (Manheimer, 1992)

The demographic culture of the participants in the study was white, middle class, Canadian. Families were important. Competence and doing the right things were also meaningful personal abilities. These descriptors do not illuminate the
passion, thoughtfulness, ingenuity, and strength which shaped the women's lives as caregivers. They were women who changed with the demands of caregiving (Pearlin, 1992), and were challenged to construct their sense of identity to match.

The women in this study experienced some loss of self and confusion about their identity when their focus was exclusively on the family member and the needs of caring. L in particular expressed how she was confused by who she is now that her husband has moved out of the house. Pearlin (1992) found a similar sense of loss in spouses and younger caregivers who became engulfed in the caregiver role. The uncertainty of the progress of the dementia contributed to the loss of self and created a perception that relating to the family member was a waiting game. Garwick, Detzner, and Boss (1994) described this as the difficulty of dealing with the ambiguous nature of dementia (particularly Alzheimer's disease). It was the uncertainty of planning and time which created a feeling of being on personal hold. This loss was soothed by time to adjust and doing new things. For some of the caregivers it was diminished by taking time to pursue personal activities. Similarly, Martire, Stephens, and Atienza (1997) also noted that time away (at work) created a buffer for the stress and role emersion caregivers experienced.

Core or relational self.

In the last few years there has been a growing discussion about the concept in the constructivist theory that there is no core self. The benefit of removing the idea of a core self is the narrative therapy approach that human beings have hope and freedom because they are constantly in the making. They have power over how life is lived. The idea is revolutionary to the boundaries of psychological thought. For the purposes of this research, however, it is enough to acknowledge that the self is in flux. As Galjan notes (1998) it is in the constructivist tradition to maintain tension between several viewpoints. In this spirit, I will leave the exploration of this changing core, or alternately the eternally relational self to other endeavors. The hope and freedom of narrative constructivism is available to the participants to the extent to which they want to grasp it. The caregivers were aware that their sense of self and identity were
shaped by their experiences and their choices. They experienced the benefits of this viewpoint.

Self care.

If the caregiver is in a never ending process of becoming who they are by interacting with the world around them, then they may have some control over their identity in different situations. How a caregiver approaches the process of living with a family member with dementia influences the continued trajectory of one’s life. The caregivers in the study felt this was an important point. They wanted to gain understanding, deal with unfinished business in their beliefs and emotions, and move on with living. Strategies for self care were one way that the caregivers actively shaped their caregiving experiences. This was also cited by Reeves (1999) as a method to maintain balance, growth and nurturing in life. The participants discussed and implemented different ways they could practice self care.

In this process, some of the group members experienced a psychological shift around the idea of self care. At first self care was justifiable if it could be seen to help the care recipient. Although, all the participants voiced the belief that they were as important as their family member, this did not translate into taking action to fulfill their personal needs (maybe despite a cost to the other). The group discussed possible self care strategies during the sessions, and after the few weeks of research, it seemed that implementing these strategies was more of a reality for the participants.

Part of self care was dealing with negative emotions. The caregivers were aware they sometimes felt guilty, angry or frustrated and wanted to find ways to change the feelings. The group was used as a forum to go through this process. Guilt in particular was an emotion that surfaced during the first three sessions of the group. Through discussion and clarification, some group members were able to put their feelings into a different perspective. They reported feeling less harassed by the emotion. This was primarily accomplished by externalizing the emotion and creating a cognitive reframe. It tested the guilt to see if there was actually something the caregiver could do to change the situation. If there was not, then the caregiver gave
the emotion a different meaning, by negating its validity. This is an example of cognitive reframing and externalizing the guilt which are techniques used in White’s (1998) narrative therapy. The caregiver’s experience with handling emotions fits well with MacRae’s (1998) study of managing emotions and the effect on self. Their inability to live up to their expectations of handling (particularly negative) emotion, impacted negatively on their sense of self. The reverse was also true in that handling the emotion in a new way impacted positively on the how the caregivers felt about themselves.

Self care involves strength. “Strength is the ability to acknowledge, clarify and meet your needs. It is developed by learning to respond to both yourself and others, resulting in response-able people. Strength involves flexibility.” (Reeves, p.4) As seen above however, strength and personal energy were precious commodities to the research participants. “Those who care for a family member with special needs may find that their survival needs are so great that they would never have much life enhancement energy. These situations call for creativity.” (Reeves, p.19) Creating strength and energy calls for the same type of ingenuity which the caregiver uses every day to tackle day to day caregiving problems. It is this strength, in the end that allows for the possibility of a new, more satisfactory story.

A Research and Therapy Method

Creating a collective narrative was both a method of data collection and a therapeutic intervention. In terms of research, the collective narrative was a means to study the connection between life story, worldviews and sense of self in caregiving. The life narratives shared were a way to explore the personal and collective worlds of the participants. They shaped their narrative using their thoughts, emotions, culture and personal history. Then when viewed as a therapeutic intervention, their narratives influence the participants lives, by ‘framing their perceptions and awareness’. This in turn gives the participants new goals and meanings. It is an ongoing reciprocal process of becoming.
The research group.

It is clear from this study, that narrative research can take place as individual case studies or in a group context. For the creation of the collective narrative, the group context was a necessity. The caregivers noted that this format was an appreciated support to them. It allowed for interpersonal learning and emotional support. Unlike Gonyea's findings in 1989, this group helped its members gain a new perspective about negative emotions. The group members learned new strategies and were more accepting of themselves in this regard. The group also encouraged self care strategies and seeing the time of caregiving as part of a larger context. These were outcomes outlined by DeVries, Birrin, and Deutchman (1995) in their life review groups.

It was my goal to include the caregivers as equal research participants during the group process. It is safe to say this was accomplished when one of the participants noted "If we write these stories we are doing the whole thesis for her." (session two). Using narratives as the method of data collection was a useful way to address the critique from O'Connor's study (1999) that caregivers sometimes feel their expertise are not recognized in support groups. In the end, it was not the narratives, but the free discussion which brought out the liveliest interaction among the group members. The participants were challenged to become active participants, find their own voice as caregivers and combine this into a communal voice as discussed by Mischler (1986) and Myerhoff (1982) in their work.

Narratives: Individual and collective.

Writing an individual narrative was a challenge for the group members. It was a risk to present themselves through their stories of caregiving. Once they found acceptance in the group, writing and reading the narratives was a positive experience for the participants. It created a sense of accomplishment and mastery. It clarified new insights. Some participants mentioned an emotional catharsis and a sense of wholeness as human beings. The acceptance which the caregivers received in the group was a validation of their experience. Creating the collective narrative in the last
group had a similar feel. Added to the above process was a feeling of negotiation and compromise. Each paragraph was read and discussed. Some of the ideas resonated immediately, like the motivation to love as the relationship continued or the sense of emotional upheaval when the family member moved away. Other paragraphs included more discussion. Do we really identify ourselves as self-sacrificing? What does it look like if we make certain choices (i.e. to visit often, or to bring the family member home on weekends)? These were the moments of collective reflexivity. Through the discussion, and rewriting process the caregivers felt a sense of ownership of the story. How the narrative was presented and what was included mattered to the participants. Even more than the acceptance of the individual stories, the collective narrative was based on a bond of belonging and connection for the group members. It could not have been created, as the caregivers might not have been active participants, without an existing feeling of community. Not everything in the story applied to each caregiver. For example, the strength of a religious faith was not a resource for one of the caregivers. Regardless, there was a willingness to include points in the story if they were significant to part of the group.

In another sense, the group members took the outline I presented as an initial collective narrative as my narrative contribution to the research group. It was how I distilled and made meaning of the experiences from the weeks of the research process. At first this perception, that it was my created individual narrative, prevented the caregivers from taking hold of it and giving feedback to change it. The culture of the group was kind. Eventually the caregivers worked more with the ideas in the narrative and less with the idea that it was my personal narrative.

The understanding, empowerment, personal expression, externalizing and clarification moved the caregivers on a path of “integrating the newness of life more thoroughly.” (Reeves, 1999, p. 4) It may allow them to ride the waves of caregiving with more calm assurance.

Hermans and Kempen (1993) wrote about the myriad of collective voices in modern society. The collective narrative from this thesis is one such example. It is a collection of water droplets which merge into a larger drop. Each individual is
represented, but the boundaries between them have apparently disappeared. Using the individual narratives first in the group was a valuable way to maintain the individual and lead to the collective.

One of the caregivers expressed an interesting concern in our last interview. She was very supportive of the process of writing and sharing individual stories. Of the communal story, however, she said "It would be a shame to think that all people's personal stories could be squished into one story." I read this as a concern that individual choice and personal response will be lost in the creation of one story. This is an important concern when writing communal stories. My response was that my intent is in no way to make individuals disappear. I want to validate the experience of each person. So how does this intention fit into the process of a communal story? It is not as much a paradox as it at first appears. Writing a collective story in a group is intended to allow the participants to take group ownership of defining themselves through the group experience and the group process. They are each a significant part of a whole. The individual is not lost, but like the analogy of the parts of the body, is an inseparable part of defining the whole. The intent is to use this process to build community at the group level, and to try using this method to get to the essence of a life experience that effects many people. Our communal story is trying to approach the essence of caregiving for this small research group. I think methodologically, the question of individuals disappearing into a group should not be overlooked. It is interesting that the exercise had the opposite effect than I intended for one participant. I suspect that her exclusion from the last few sessions, the spouse's voice in the story and most importantly, her exclusion from the group process of the communal story, had an influence on her concerns. Regardless, it is an issue I would like to watch in future groups.

When planning the group there was some question about the heterogeneity of the participants (Committee meeting, Aug. 1, 2000). The trend in research in the last few years has been to look at very specific groups of caregivers when dealing with dementia. For example, there are differences in the experience of daughters caring for a parent as compared to wives caring for a husband. These studies have provided
valuable information about specific situations and the impact that relationship has on the experience. The emphasis is slightly different when writing a communal story. Heterogeneity increased the richness of the descriptions and the story itself by broadening the font of experience. The fact that the participants were in four different stages of caregiving did not diminish commonalities in the shared experiences. It did however add to the overall perspective of the group story. It tapped into commonalities of experience that became communal knowing. "I know this experience and I see from what you said that you know it too." As mentioned above, it is important to include the reading of each individuals story in the group, otherwise there may be a danger that participants will feel their individual voice is lost. As it was, the individual voices were strengthened in the creation of a communal story that each participant can take some ownership in; where the individual voice is magnified as part of the group.

Another aspect for consideration is the im-permanence of the stories. Each story is a reflection of the author's experience and meaning at the time that it was written. It is a moment in time. If the authors were to write their story again, today, it may have a different slant due to changes in life and the way they make sense of it. What I report about an event as I reflect back on it, may not be what I would have reported at the time. So what is the benefit over time, if the stories are not a true long term reflection of the participants? Therapeutically, writing and reflecting on the story brings understanding and distance which may provide space for more choices to be made. Reading the story in the group brought a sense of belonging and personal voice to the participants. Otherwise, the stories are an accurate depiction of each person in that moment of time, which is valuable in and of itself when exploring the topic of caregiving.

Collective narrative as definitional ceremony and reflexivity.

The power of writing a narrative lies in its reflexivity. Myerhoff and Ruby (1982) looked at definitions and uses of reflexivity in the book *A Crack in the Mirror*. Being reflexive is commenting on my experience of an experience. Storytelling is an example
of an old tradition with this type of description. It makes subjectivity explicit in the
telling of an event. (e.g. This is what happened to me, and this is how I felt about it.)

The value of reflexivity is that it combines self awareness with the implications of
this awareness to the context at hand. Making meaning of this self awareness in
context is a creative process. Creativity is often involved in change. So, a possible
model of transformation is engaging in a reflexive process, using observations on an
experience to create meaning about self in context, and letting this guide personal
choices about self development and change. Seeing the influences of self, awareness
and context on each other is important for a "critical and sophisticated understanding"
of being (Ruby & Myerhoff, 1982, p. 6) which is alive with possibility. Reflection, on
the other hand, lacks the significance of context. Simple reflection is self awareness
without the added level of the implication of this knowledge in a context. It is possible
to reflect on a situation without change. This is why an exercise in reflexivity, and not
reflection, is a more useful therapeutic approach. It can bring about choice, possibility,
and change of self in context.

In this study being reflexive was joined to writing a narrative. As mentioned
above, it is not only a form of therapy, it is also a research method. It presents
information in a purposive manner. The author reveals what she chooses to show.
What is presented "reveals to the audience the underlying epistemological
assumptions that cause the formulation of the process (questions, answers and
presentation) in a particular way" (Ruby & Myerhoff, 1982, p.6). Through narrative,
researchers can gain descriptive knowledge of the author, the context, and themselves
by interpreting and recording the process.

Participating in a definitional ceremony, such as a collective narrative, lets the
research participants create a collective "interpretation of themselves...and succeed in
convincing themselves (and the audience) that this is a true picture." (Myerhoff, 1992,
p. 34) As we are in a constant process of co-creation, the group interpretation is the
true picture in that moment.

Narrative and collective narrative are forms of art. They are the active creation
and definition of reality, self and identity. Having said this, it is important to distinguish
between narrative and fiction. "Stories of personal identity differ from literary productions in that they are constructed within an unfolding autobiography and incorporate the accidental event and unintended consequences of actions." (Polkinghorne, 1991, p. 135). Events and consequences occur which are not created or planned. It is the meaning of these events that are created.

Collective narrative as ritual.

The collective narrative and the definitional ceremony have aspects of a traditional ritual. Rituals have the purpose of enhancing the personal or social meaning of an event. They are used to help people through transitions and sometimes to ease the pain of a change (Reeves, 1999). Participating in a collective narrative is one such defining, time-limited event. The benefits felt by the participants of this collective narrative group coincided with many of the benefits listed by Reeves of a traditional ritual. [I have substituted the word experience for the word grief.]

If ritual is done well, it can help us in the following ways:

- It can legitimize (experience) and different types of (experience)
- It can provide structure and stability during chaos and instability.
- It can raise self-esteem, as participating shows us as positively impacting on the world.
- Being time-limited, it can offer safety, allowing expression of emotion.
- It is a potent honouring of a person, relationship, or issue
- It can clarify issues and encourage changes in attitudes and behaviours
- A sense of direction or meaning in life may emerge
- At a time when we feel disconnected or different from others, it can give us a sense of community as others support and witness our process
- It promotes congruency (body, mind, emotions, spirit working together)
- It provides motivation for growth by participants making public statements of intent for change. (Reeves, 1999, p.33)

The collective narrative also seems to be flexible enough to encompass caregivers at different types of transition. Van Gennep (1960) wrote about three types
of ritual for life transitions. Transition is put into a context of crossing a threshold (or the latin word limen). There are preliminal rituals as a way to prepare for an experience. Liminal rituals are for during the pivotal experience, and postliminal rituals are a way of letting go of the status of the experience. From the point of view of the research group, the transition is the period of caring for a family member with dementia. None of the participants were in the preliminal stage. There were three in the liminal stage (caring for the person in the present), and one in the postliminal stage (integrating a new life after the death of the person). Yet the act of creating a narrative and a collective narrative was seen as meaningful and affirming by all the participants. Reeves would not predict this. Rather to participate in a ritual at the ‘wrong’ time can alienate the participant. They may feel misunderstood or guilty for not having a required response (Reeves, 1999). The ritual does not meet the person in her present psychological space and is therefore disrespectful. On the other hand the participants were not in different stages if the task is viewed as creating meaning and identity for the experience of caregiving as a whole. This may explain why there was no incongruence felt by the participants when writing the collective narrative.

Finally, the collective narrative has some of the same goals as a traditional ritual. Rituals "take us out of our normal lives, inviting us to a closer, purer connection with ourselves, our world, and the source of all that is. ... This process encourages us to stretch our limits and change unhelpful attitudes, beliefs, and behaviours." (Reeves, 1999, p. 32) Reflexive narrative does much the same thing.

Successes and Limitations of the Study: Future implications for research

The success of the study was that it created a rich description of the participant’s meaning and sense of self when caring for a family member with dementia. The three activities of participating in a research group, writing a personal narrative of caregiving, and creating a collective narrative of the group were seen to be helpful both in collecting rich qualitative data and in providing a therapeutic space for the participants to make sense of their experience. It is important to note at this point, that the facilitators who undertake a this type of research must be well versed in the
skills needed to run a safe group. The facilitator is responsible for ensuring that the group experience is respectful to all participants and that sensitive personal material is debriefed appropriately.

One limit of the study included the self-selecting nature of the participants. They were all women who had been in support groups before, and who saw the challenge of the research group as being inherently meaningful. For them it was. It provided them with a space to fulfill their personal goals in joining the group, while adding to the collective knowledge of caregiving. Although the exercise of writing narratives would in theory be universally beneficial, different configurations of individuals may find the group more or less useful.

One critique of narrative in general is that it's use is ethically limited to postmodern Western culture (McAdams, 1996). Modern Western culture and other ethnic groups which value a set of constant epistemological truths, may not be comfortable with the idea that the group is creating a new identity; or the identity created in a collective narrative may be pre-imposed by cultural expectations. The group of caregivers in this thesis study were part of the Western culture, but may not have previously been exposed to postmodern ideas. From their responses to the ideas presented in the group, my assumption is that the three elderly participants had not studied philosophy in the recent past. Although this may have been the case, the research experience was successful. Social constructivism acknowledges the influence of culture on the individual. It may be a broad enough perspective to allow for non-"Western" constructions of group identity. If it can accept the identity the participants create for themselves. Working within set frameworks would probably limit the possibilities of identity which a given group may embrace. These limitations exist to some extent in postmodern constructionism, as participants censor their narratives to protect their family member or present themselves in a personally acceptable light. An example of this was when V moved quickly over her husband's experience in the psychiatric ward with the phrase "Well, we won't get into that." In that sense culturally acceptable presentation was a limit to the study.
As mentioned in previous chapters, the absentee rate had some influence on the creation of the collective narrative. Although the participants said they did not feel alienated by their absences, the collective narrative would have been slightly different if all participants had been present. The fact that it was the daughter caregiver who was not able to be part of the last session (where the collective narrative was refined) may be symbolic of her feelings of difference from the wife caregivers. I attempted to include the daughter in the collective narrative by taking the narrative to her separately, making a few changes, and doing a member check with the other three participants. Regardless, this was less than ideal in the creating of the collective narrative culture of the group.

This follows into another limitation of the study. There was only one week to complete the collective narrative in the group setting. In the original plan there were two weeks set aside for this purpose. In future groups, I would plan more time for the creation of the collective insights and identity of the group. It may remove some of the pressure to produce a product and increase the time for interpersonal group identification. Along those lines, I would also like to try bringing a less completed outline as a basis for the collective narrative. In this study I created a rough draft for the participants as a spring-board for the collective narrative. This was seen as helpful by the group. I would, however, like to try presenting a group with a more nebulous process, where the content is produced spontaneously by the group member. They have been part of the ongoing process and it would be interesting to see which parts of the emerging research questions and insights the group members integrated and retained without the prompting of my outline.

A final limitation may be the dependency of narratives on verbal or literary expressiveness. One of the women in the group asked if I could transcribe her narrative, as English was her second language. This potential difficulty was easily overcome. It would be interesting, however, to look at other forms of creative expression when creating collective narratives with groups where language is a barrier.
Conclusion

This is all part of the story about what it has been like for the last ten years or so to be me, and before anybody else has the chance to ask it, I will ask it myself: Who cares? What in the world could be less important than who I am and who (my family was), the mistakes I have made together with the occasional discoveries, the bad times and the good times, the moments of grace. If I were a public figure and my story had some impact on the world at large, that might be some justification for telling it, but I am a very private figure indeed, living very much out of the mainstream of things in the hills of Vermont, and my life has had very little impact on anybody much except for the people closest to me and the comparative few who have read books I've written and been one way or another touched by them.

But I talk about my life anyway because if, on the one hand, hardly anything could be less important, on the other hand, hardly anything could be more important. My story is important not because it is mine, but because if I tell it anything like right, the chances are you will recognize that in many ways it is also yours. (Buechner, 1992, p. 321)

When we began on the road of this thesis, the purpose was to explore caregiving, meaning and identity. The journey was marked by personal narratives and interpersonal interactions in the research group. It culminated in the creation of a collective narrative of caregiving experience. As has been shown by the pages of rich description and ideas, that the caregivers shaped their identity to meet the demands of informal caregiving. They made meaning of their experiences which helped them to become who they are.

The research itself had an impact in creating choices for the caregivers. It provided a space where new insights were made and new possibilities for continuing life as a caregiver were voiced. Although the research was challenging to the group members, it created a sense of accomplishment and connection. Part of the choices created came from an awareness of the paradox of the caregiving experience. The
research highlighted how it is possible to hold opposing caregiving experiences in tension. For example, the person with dementia is physically present, but has lost substantial mental abilities. Another continuous tension is balancing the wish to keep the family member at home with the desire to have personal time and space. A final paradox concerns the mixed emotions caregivers sometimes experience in loving and hating their family member in a short space of time. These are the counter-intuitive realities of living as a caregiver of someone with dementia.

The research was based on several constructivist and narrative theoretical assumptions. The caregivers were able to create the present stories and view the possibility of new stories. Life purpose, sense of self and identity are partially embedded in culture and society (McNamee and Gergen, 1992). In a meaning-makings orientation, sense of self and life purpose are a constant interplay of constructed meaning of life experiences, which are created individually and in concert with other human beings (Rosen and Kuehlwien, 1996). It is this meaning which the collective narrative, as a reflexive extension of Myerhoff’s definitional ceremony (1982), brought to the field of research. As both a research method and a therapeutic tool, the narratives in this thesis speak to the world of the life transition experience of caring for a family member with dementia. Future research and support groups using collective narrative will expend on the process and uses of meaning and identity definition in small and large cultural settings.

In the past pages the stories of the small group of caregivers have been explored in detail. This research and support group met for a few weeks to discuss the experience of caring for a family member with dementia. We shared individual stories, went where the conversation took us, and examined specific issues in some detail. Five themes for the collective narrative emerged through the research. These were: the struggle with practical aspects of caregiving, the caregiver’s life in community, health in caregiving, shaping caregiving issues in the research group, and examining the research experience.

The group was a sharing of life experiences and a meeting of unique minds. Each person had a slightly different reason for taking part in the group - beyond the
stated one of helping me with my research. Each person brought a slightly different point of view which created the richness of the group as a whole. We had people at various stages of being a caregiver; in the sense that they were caring for their loved one at various stages of the disease (or caring for themselves after the disease had completed its job and the loved one had passed away). We were curious and learned from each other. The group encouraged the issue of self-care, and to validated the researchers by providing a place for their voices to be heard.

The stories help illustrate what caregiving is like for the authors: the joys and sorrows, as well as the meaning, learning and identities that were part of the process. There are some similarities in the stories which allowed for mutual support and built community in the group. Differences were also present and were particularly evident in how each person brought themselves to bare in their creativity of dealing with this process. The collective narrative is the new gift of the researchers to the field of narrative and caregiving. It sketches both the experience of being in the group and of living the caregiving life as was gleaned from the images and perceptions we shared.

We learn through stories and can use this learning in the continuing creation of our lives. It was my hope that this research group added insight into the life transition of caring for a family member with dementia. Insight which will be helpful to the participants and readers alike. It may also give a human face to the universal experience of love and loss as it presents itself in the particular window frame of living with dementia in the family.
References


Story-telling and story-listening
Quotes from *Listening to Your Life* by Frederick Buechner

Our Stories (p. 321)
"This is all part of the story about what it has been like for the last ten years or so to be me, and before anybody else has the chance to ask it, I will ask it myself: Who cares? What in the world could be less important than who I am and who (my family was), the mistakes I have made together with the occasional discoveries, the bad times and the good times, the moments of grace. If I were a public figure and my story had some impact on the world at large, that might be some justification for telling it, but I am a very private figure indeed, living very much out of the mainstream of things in the hills of Vermont, and my life has had very little impact on anybody much except for the people closest to me and the comparative few who have read books I've written and been one way or another touched by them. But I talk about my life anyway because if, on the one hand, hardly anything could be less important, on the other hand, hardly anything could be more important. My story is important not because it is mine, but because if I tell it anything like right, the chances are you will recognize that in many ways it is also yours."

Your own journey (pp.10,11)
"What I propose to do now is listen to my life as a whole, or at least to certain key moments of the first half of my life thus far, for whatever of meaning, ... there may be in it to hear. My assumption is that the story of any one of us is in some way the story of all of us. For the reader, I suppose, it is like looking through someone else's photograph album. What holds you, if nothing else, is the possibility that somewhere among all those shots of people you never knew and places you never saw, you may come across something or someone you recognize. In fact - for more curious things have happened - even in a stranger's album, there is always the possibility that as the pages flip by, on one of them you may even catch a glimpse of yourself. Even if both of those fail, there is still a third possibility which is perhaps the happiest of them all, and that is that once I have put away my album for good, you may in the privacy of the heart take out the album of your own life and search it for the people and places you have loved and learned from yourself, and for those moments in the past - many of them half forgotten - through which you glimpsed, however dimly and fleetingly, the sacredness of your own journey."

That Deep Place Inside Us (p.317)
"I have called the third ... memoir Telling Secrets because I have come to believe that by and large the human family all has the same secrets, which are both very telling and very important to tell. They are telling in the sense that they tell what is perhaps the central paradox of our condition - that what we hunger for perhaps more than
anything else is to be known in our full humanness, and yet that is often just what we also fear more than anything else. It is important to tell, at least from time to time, the secret of who we truly and fully are - even if we tell it only to ourselves - because otherwise we run the risk of losing track of who we truly and fully are; and little by little come to accept instead the highly edited version which we put forth in hope that the world will find it more acceptable than the real thing. It is important to tell our secrets too because it makes it easier that way to see where we have been in our lives and where we are going. It also makes it easier for other people to tell us a secret or two of their own, and exchanges like that have a lot to do with what being a family is all about and what being human is all about.”

Words [and experience] (p.48)
Writing is experiential. It draws you past your mind into your body to use all your senses to recall an event (emotional and otherwise). Writing and sharing then becomes an opportunity to re-create yourself. “Words - especially .... words that have to do with the depth of things - get tired and stale the way people do. Find(ing) new words or put(ing) old words together in combinations that make them heard as new, make you yourself new, and make you understand in new ways.”

Art (p. 51)
“In effect he puts a frame around the moment, and what the frame does is enable us to see not just something about the moment but the moment itself. ... The frame sets it off from everything else that distracts us. It makes possible a second thought. That is the nature and purpose of frames. The frame does not change the moment, but it changes the way we perceive the moment. It makes us NOTICE the moment, and that is what (the author) wants above all else. It is what literature in general wants above all else too.
From the simplest lyric to the most complex novel ..., literature is asking us to pay attention. In sum, pay attention to the world and all that dwells therein and thereby pay attention to yourself and all that dwells therein. ...
Literature, painting, music - the most basic lesson that all art teaches us is to stop, look, and listen to life on this planet, including our own lives, as a vastly richer, deeper, more mysterious business than most of the time it ever occurs to us to suspect as we bumble along from day to day on automatic pilot.”
Paying attention is a way to express love and value for something or someone.

Power of Words (p. 170)
“If Literature is a metaphor for the writer’s experience, a mirror in which that experience is at least partially reflected, it is at the same time a mirror in which the reader can also see his or her experience reflected in a new and potentially transforming way. ... Words written fifty years ago, a hundred years ago, a thousand years ago, can have as much power today as ever they had it then to come alive for us and in us and to make us more alive within ourselves. That, I suppose, is the final mystery as well as the final power of words: that not even across great distances of time and space do they ever lose their capacity for becoming incarnate.”
The Truth of Our Stories (p. 305)
"In the long run stories all overlap and mingle like searchlights in the dark. The stories (you tell) are part of the story (you are), and the other way around. ... My story and your story are all part of each other too if only because (we have spent time together) and seen each other's faces so that we are at least a footnote at the bottom of each other's stories.
In other words all our stories are in the end one story, one vast story about being human, being together, being here. Does the story point beyond itself? Does it mean something? What is the truth of this interminable, sprawling story we all of us are? Or is it as absurd to ask about the truth of it as it is to ask about the truth of the wind howling through the crack under a door?"

Summing Up (p. 319)
"It is easy to sum up other people's lives, ... and necessary too, of course, especially our parent's lives. It is a way of reducing their giant figures to a size we can manage, I suppose, a way of getting even maybe, of getting on, of saying goodbye. The day will come when somebody tries to sum you up the same way and also me. Tell me about old Buechner then. What was he really like? What made him tick? How did his story go? Well, you see, this happened and then that happened, and then that, and that is why he became thus and so, and why when all is said and done it is not so hard to understand why things turned out for him as they finally did. Is there any truth at all in the patterns we think we see, the explanations and insights that fall so readily from our tongues? Who knows? The main thing that leads me to believe that what I've said about my mother has at least a kind of partial truth is that I know at first hand that it is true of the mother (person) who lives in me and will always be part of who I am."
**Memory**

Remember (Identity)

“When you remember me, it means that you have carried something of who I am with you, that I have left some mark of who I am on who you are. It means that you can summon me back to your mind even though countless years and miles may stand between us. It means that if we meet again, you will know me. It means that even after I die, you can still see my face and hear my voice and speak to me in your heart. For as long as you remember me, I am never entirely lost. When I am feeling most ghost-like, it's your remembering me that helps remind me that I actually exist. When I'm feeling sad, it's my consolation. When I'm feeling happy, it's part of why I feel that way.

If you forget me, one of the ways I remember who I am will be gone. If you forget me, part of who I am will be gone.”

Uses of Memory (p. 323)

“I am inclined to believe that (the) chief purpose of... memory is to enable us to go back in time so that if we didn’t play those roles right the first time round, we can still have another go at it now. We cannot undo our old mistakes or their consequences any more than we can erase old wounds that we have suffered and inflicted, but through the power that memory gives us of thinking, feeling, imagining our way back through time we can at long last finally finish with the past in the sense of removing its power to hurt us and other people and to stunt our growth as human beings. The sad things that happen long ago will always remain part of who we are just as the glad and gracious things will too, but instead of being a burden of guilt, recrimination, and regret that make us constantly stumble as we go, even the saddest things can become, once we make peace with them, a source of wisdom and strength for the journey that still lies ahead. It is through memory that we are able to reclaim much of our lives that we have long since written off by finding that in everything that has happened to us over the years (we are offered) possibilities of new life and healing which, though we may have missed them at the time, we can still choose and be brought to life by, and healed by, all these years later.”
Take Care of Yourself (p. 320)
"Love your neighbour as yourself is part of the great (Christian) commandment. The other way to say it is, Love yourself as your neighbour. Love yourself not in some egocentric, self-serving sense but love yourself the way you would love your friend (in the sense of taking care of yourself, nourishing yourself, trying to understand, comfort, strengthen yourself.) ...People in caring professions in general, are famous for neglecting their selves with the result that they are apt to become in their own way as helpless and crippled as the people they are trying to care for and thus no longer selves who can be of much use to anybody. If your daughter is struggling for life in a raging torrent, you do not save her by jumping into the torrent with her, which leads only to your both drowning together. Instead you keep your feet on the dry bank - you maintain as best you can your own inner peace, the best and strongest of who you are - and from that solid ground you reach out a rescuing hand. “Mind your own business” means butt out of other people’s lives because in the long run they must live their lives for themselves, but it also means pay mind to your own life, your own health and wholeness, both for your own sake and ultimately for the sake of those you love, too. Take care of yourself so you can take care of them. A bleeding heart is of no help to anybody if it is bleeding to death."

The Deepest Self (p. 325)
"Life batters and shapes us in all sorts of ways before it’s done, but those original selves which we were born with, and which I believe we continue in some measure to be no matter what, are selves which still echo with the holiness of their origin. I believe ... that this original self, ..., is the most essential part of who we are and is buried deep in all of us as a source of wisdom and strength and healing which we can draw upon as we choose, or in our terrible freedom, not draw upon as we choose. I think that among other things all real art comes from that deepest self - ...all of it that in some way nourishes the spirit and enriches the understanding. ...And I think that from there also come our best dreams and our times of gladdest playing and taking it easy and all those moments when we find ourselves being better or stronger or braver or wiser than we are."
Possible Themes and Questions from Session One

- There are stages of being a caregiver, which influence the stages of your personal life.

- "Giving the best care is very important." V.

- The process of caregiving has physical and emotional effects; of which the caregiver needs to be aware.

- Moving a family member into a care home is very difficult for the caregiver. For spouses it is the end of a part of the marriage. For children it is the end of some of a parent's independence.

- Expectations and guilt around giving care are a common experience. Where do they come from? How do they affect us?

- We have a belief that too much self-sacrifice (i.e. Personal Health) is not a good or productive thing.

- We have a belief that support and connection with other caregivers is important to living and coping.
Handout Session 2: Writing Exercise
February 28, 2001

Writing your story of the experience of caregiving

Sit down and spend some time appreciating yourself and your journey as a caregiver. When you think about it, what comes to mind? The time, the places, the feelings, or anything else that has been part of this experience for you. As you think, jot down your reflections in a booklet or on paper. This is the beginning of your caregiving story. Over the next week, add to your notes when other things come to mind. Some people like to spend a set amount of time each day writing a journal of their experiences. Use a method that you know will fit for you.

This is a free exercise of exploration. Let yourself be curious about any and all parts of your experience. You may be surprised by what you discover. In the beginning phases it is important not to edit yourself too much. You will need to decide later what you want to include in your final story and what you want to leave out. I encourage you to try the process. The story you share with the group will only include what you feel comfortable reading out loud.

Stories have a structure. The following may be things you can use to write your personal story: What are the ‘facts’, the characters, the plot, the beginning/middle/end of the story, the challenges and resources, changes of roles, feelings (loss, grieving, grateful moments), support systems (people and things), your best times, your worst times, what you have gained (resources and wisdom), hopes and disappointments, who you are (now and then), the reasons you have for caregiving, the meaning you give to caregiving, what you would like to keep secret about the experience, what you would like to tell yourself and others about caregiving.....

Your ‘final’ caregiving story can be as long or as short as you would like. Two -five pages may be a good goal. It can also be in any form you like, and can include any props you feel are important to sharing the story with the group. This could include pictures, songs, or things that are part of your experience.

Be kind to yourself. Writing a story like this can be exciting, but it can also bring up strong thoughts and emotions. This is a normal part of the process. Give yourself time and permission to let it this happen. You probably already have a support network of friends to talk to. You can call me anytime if something comes up for you, or you would like help transcribing or writing your story.
Themes and Questions from Meeting Two

1. The timing of moving your family member into a facility is important.
   At the time you want to keep the family member at home as long as possible because:
   - it is the wish of both the family member and your wish as Caregiver (familiarity and comfort of home)
   - it prevents loneliness and a change in the role of the couple
   - personalized care is best
   This is balanced against hindsight which says, the benefits of having the family member in a facility are
   - the strength of a combination of care between the facility and the caregiver
   - maintaining your health
   - having more personal and social time
   The emotional process of the transition to a facility.
   - there are sometimes feelings of anger, resentment, and abandonment towards the family member due to the change and the extra responsibility.
   Question: What do you do with the inevitable conflict between the wishes of your family member and yourself vs. The emotional and physical ‘reality’ of the situation?

2. There is a natural focus on spending time with the family member
   - Two kinds of Grief: Anticipatory grief: “dying inch by inch”, and grief (expressing emotion to heal and go on with life)
   - A positive of the long process is that it allows time to say goodbye, and appreciate the quality of the person’s entire life.
   - The fun process of talking about things I dream to do.
   Question: Who am I (with or without my relationship to my family member)?
   “I lost my personality. My being is focused on him.”
   Questions: How have I shown love and support? What does showing love and support look like? Is this the only way? Or is it the way I want to?
   "If your husband is taken care of, why is it hard to do other social things?"
   - being apart is hard
   - the disease is unfair, and I want to do what I can to make up for that.

3. Past family dynamics have an influence on the relationship now
   - who was the driving force in the relationship?
   - “I realize it is a way to gain acceptance from my family member.”
Guidelines for Listening to People's Stories:

1. Keep in mind the purpose of the group: To share the experiences we have as caregivers.

2. No interruptions during the telling of the story.

3. Positive feedback only at the end of the story.

4. No editing other's stories. (The writer does this).

5. Don't feel that everyone needs to comment on the stories.

6. Maintain confidentiality of the content of the stories.
Handout for Session 4: Outline
March 14, 2001

Themes and Questions from Session Three

- family dynamics
  old patterns and roles, (critical mother/child)
  support from family members

- new roles
  choosing to change

- finding comfort
  in the realization that the person had a good life before the disease

- social support
  social workers, Dr., respite facilities, God

- Grief
  "First we grieve the husband we lost, then we grieve the person we cared for"
Handout for Session Five: Outline
March 28, 2001

Agenda for Meeting Five

Looking back at the past five weeks, we have spent some time exploring the experience of Caregiving. This is a meeting to appreciate you and the work you have done. It is also a time to bring the group to a close and say goodbye.

Themes and questions from Session Four (see handout)

Our story

We have talked together and learned to know each other over the past few weeks. The time we spent together creates a communal story. We have had subtle influences on each other, and on how we view our lives. I'd like to spend some time looking at the story we have created together.

• How were your experiences similar? What did they have in common?
• How were your experiences different?
• What is the meaning of your story in terms of your life journey?
• How does the process of caregiving create meaning for you?

Feedback about the group

• What is your impression of the group over the last few weeks?
  What did you like?
  What would you have preferred to have done differently?

• What was your experience of story writing?
  Was it what you expected?
  What was it like to share your story with the group?

Saying Goodbye

• Where to go from here.
• The story booklets.
• A chance to comment on anything else.
Themes and Questions from Session Four

- There are different kinds of loneliness:
  Physical (going home to an empty house) vs. Discussion

- Social stigma: Some people in society were judgemental when the family member was moved to a care facility: They saw it as abandonment, that facilities are ‘bad’.

- Not being able to please the family member is a source of sadness. i.e. She wants to come home, but money or health dictate otherwise.

- You get used to seeing sickness - and don’t notice when it gets worse (an outsider, the Dr. saw it first.)

- It is better to keep the family member at home or in the facility?
  Separation is hard, physical exhaustion is not an easy way to live,
  If the care home is safe and well-run it is better to live apart
  (when looking at the long term perspective)

- meaning
  justify experience with disease: “others have it worse”
  find different types of communication meaningful
  to do the best I can because I love this person.
  This is part of our life together

- frustration about behaviour
  wandering and getting lost, safety and respect
  “getting into things” at home, childish behaviour

- “knowing you are loosing your mind must be hard” - the burden of grief shifts from care receiver to caregiver over the course of the disease

- self care
  deciding to, (changing expectations, perfectionism,)
  how to (exercise, doing nice things, get rid of personal ‘baggage’)

- caregiving
  falling into the role of caregiver by circumstance,
  believing that people are valuable regardless
  past caregiving roles
References for Personal Counselling

Our research sessions are coming to a close. Thank you for being an important participant in this study. Sometimes looking at parts of life in detail, and being part of a support group can lead to more questions than answers. You may feel that this process has ‘stirred up’ more than you thought, and you may want to talk to a counsellor about it in the weeks down the road. It is important for you to follow up if this is the case. The following are a list of counselling resources for your information. If you have any questions please feel free to contact me. All referrals are confidential.

1. Your family Doctor or Social Worker.
2. Alzheimer Society of BC - they have Regional Representatives who could meet with you or recommend a counsellor in your area:
   681-6530
3. British Columbia Psychological Association (referral service):
   730-0522
4. VGH Geriatric Psychiatry Outreach Services: 875-4728
Appendix D: The Participants Individual Narratives

Caregiving - A Moment In Time

The return to VGH Heather Pavilion brought memories of the beginning of my being a caregiver. It was 3 years ago that my mother was brought to Emergency by my sister and was subsequently admitted after tests revealed a stroke and dementia. Life and daily living for my mother changed then, as it did for me too.

My mother is a self-made woman. She fought the system when women were still delegated to being wife and mother. Her own marriage lasted only 10 years and she very capably built 5 houses including 2 duplexes, worked as a cleaning lady, and lived a full life of hard work and play. She tried to get a mortgage in the 1950’s but in those days women were not given mortgages, so she borrowed the money from a friend and repaid it within one year. There is much more to tell, but now I just want to emphasize that this woman had Grade 3 education. Her drive, common sense, intelligence, spark, curiosity, stubbornness, self-centered, manipulative, love of life made for a very interesting person.

From childhood, friends viewed me as being shy and lacking self-confidence. That was true. I never seemed to do anything right. My mother said I had no personality when compared to my older sister. She bossed me and never allowed me to grow up. When I tried to be independent, she criticized me and pointed out my failures, which in later years extended to my poor husband choice. I hesitated to make decisions for fear they would be “wrong”, and so often they were wrong. The day came when I ran away from home and lived in the Caribbean. All I wanted to do was to get away from the person who was controlling me. It was obvious - she had all the answers and I couldn’t even make coffee. She always said, “I told you so” or “You should have listened to your mother.” She still says “Listen to your mother for the first time in your life.”

Don’t get me wrong. She is a very charming person, who laughs readily and can be melodramatic, crying and sobbing just as readily, depending on the audience. She has learned to manipulate those around her. She is a performer. She says even today, “I want to be loved and that will make me better.” “People love me for my singing.” She has a wonderful voice and does give pleasure to others.

Now I have set the stage, I can now explain my inner feelings when I was suddenly aware that I had become a caregiver to my mother. I had been away on business and when I returned home I discovered my mother was in VGH Emergency having been taken there by my sister. When I arrived, my mother was in a panic and cried to be taken home. My sister made a quick exit and has continued to do so since. The staff had to physically restrain my mother and directed me to go home. My heart went out to this helpless woman. She was so frightened and confused. Her eyesight was affected and she saw things differently, i.e. her fork was a spoon. My breath was knocked out of me.
My sister, being the older one, was in her glory taking charge of my mother's welfare. She longed for the day she could take possession of her affairs. Here at last was her chance. At this point, she and I were talking to each other. I spent long hours at the hospital helping with my mother's care, which included bathing her, as she was terrified of the bathtub. The sound of running water and the jet action frightened her. She is a very private person and to be put in a room with other people was strange. She complained constantly. Everything was wrong: the food, lights, doctors, noise, clothes, etc. “Get me out of here! Please, sign me out!” “You are the only one who can sign me out.” (guilt)

Suddenly, I was the parent with a spoiled child. And just like my experience with a sick child, my emotions and sorrow surfaced. I felt helpless. I had no one to turn to. I searched out professional help and went to counselling and support groups. They helped for the moment but I didn't feel the real problem was being addressed. The hurting just wouldn't go away. I just felt sorrow, loss, in limbo, and then the anger set in. I felt ashamed to express it openly. My sister was doing one of her numbers and took possession of all my mother’s cash money and prized possessions, leaving the rest to me, “to throw away or sell” (according to her note).

I was furious and angry with my mother having put me in this position! She knew what my sister was capable of and had seen the cleaning out of 4 husbands. She would never listen to me when I tried to get her things in order. She was “able to handle her business affairs and didn’t need any advice! Now, her situation was a mess because she had not appointed a power of attorney. An expensive court battle returned the cash, but the “prized possessions” are now held by my sister, never to be seen again. More anger.

There are good days and bad days. The good ones include my singing with my mother, taking her to the opera, taking her to sing-alongs, taking her to visit friends for lunch, taking her for walks and making sure she is entertained. On the bad days she berates me and says “How could you do this to your mother”? “You will be sorry one day when this happens to you.” “I feel like a prisoner.” “I didn't deserve this.” “I worked hard all my life and I don't deserve to live like an animal in a cage.” “God will punish you for what you are doing to me.” “I beg you, please, sign me out of here.” “They are abusing me at night. How can you let that happen to your mother?” “The food is horrible.” An on and on. She has even gotten on her knees and begged me to get her out. (guilt).

I think it would be a lot easier for me if she was more ill or incapacitated, but then I feel guilty for having such thoughts. I enjoy our outings until she starts in on her negative comments, which just make me exasperated and frustrated. I become defensive and
fire back at her that she created the situation she is in by not agreeing to have live-in help, or not getting an automatic wash machine, etc. She is so stubborn and bossy and then I realize it is her illness. I try to use all the techniques recommended in the book. "Mother, I will phone you when I can. Please don't have the staff dial me." I have tried to set a schedule for phone calls and visits. Unfortunately, my own schedule is loose and sometimes I cannot be regular. I do my best.

I know I don't always visit willingly. I resent my sister not visiting. I resent that because I am labelled the 'softie', I get dumped on. My mother knows what buttons to push to get me riled up. She once phoned me at 9:30pm to say the furniture was changed. I immediately thought my sister had removed the few pieces she has with her, when I got there nothing was taken and my mother just said, "Well, now you are here, stay a while and let's talk." It was then I finally saw the manipulation. Her friends tell me what a good daughter I am. The staff says the same thing. I just feel used. I feel tired. I feel I will die before my mother. She upset me to the point I had to go to Emergency with chest pains. I felt pretty stupid telling the Emerg. Dr. a phone conversation with my mother prompted the chest pains. It was a wake-up call.

I'm resentful my sister doesn't share the burden, and yet, I'm glad she doesn't as then I can play the role of the martyr. I am not comfortable as a martyr. As I get older I prefer not to be the victim. I think my mother has compromised somewhat as she expressed her gratefulness at my taking her out for a drive to listen to opera, for example. At times she shows insight and at others, she is totally selfish and self-centered. Her general physical health is improving. Her short and long-term memory is excellent. She has regained her sense of humour. She is learning new songs and she knows the names of all the staff.

I am very sorry she is where she is. I am very sorry I cannot do more for her. I am very sorry I allowed her to influence how I feel about myself. I need to be satisfied that I do as much as I can for her and I must not jeopardize my own health as she will never comprehend what damage she can do to my health. It is never enough. The sauerkraut is always too salty. Mrs. R's family is so good to her, (inferring I am not good to her). She demands more and more. I try to be cheerful but her negativity wears me thin. The roles have not really changed. In other words, I am still the daughter who makes all the mistakes, and she is still the controlling and domineering parent. My only defense is to go away, as example, going to sea for months. My escape. She survives well. She is relatively safe and her daily needs are met.

There are moments when she is mellow and not contrary, and I realize she is not asking too much of me. That a short phone call is little to ask and not a big thing. If I change my attitude and try to be more tolerant. That life is the way it is today. The clock cannot be turned back. If I give her moments of pleasure by singing with her and visiting, I will have helped the time to pass for a free spirit, non-conformist, Margaret-Thatcher-in-disguise mother. As a caregiver, I have set limits and learned to treat myself so I don't get pulled down to a level of ill health. In order to survive, I have to
consciously resist the wave of helplessness and depression brought on by being exhausted, frustrated, tired, and self-recriminating.

I have lots of friends who have grown tired of listening to what is happening with my mother. I think secretly they wish I would grow up. Others, who have lost their mothers, confess that they could have done more for them. I hear a lot of that. One admitted she could have been more kind and less impatient.

I just feel I am in limbo. I have the feeling of unfinished business. I can't get on with life as long as this is unfinished. I dread the passing of my 87 year old mother as I will then be in another legal battle with my sister. I hope I can survive the mess that is forthcoming.

In some respects I can relate to other caregivers, and yet, there are others with situations that cause me to be in awe of what they are putting up with. I recently listened to a woman with a similar situation with her mother and she is much harder on her. She disagrees with taking her mother for a sleep-over. She says my mother will never adjust to her situation as long as I allow her to enter the normal world. Today, I disagree. Tomorrow, I may see the error of my way.
An Unexpected Sadness

Our story begins in January 1994 when my husband had a triple aorta coronary bypass graft and a resection of a right lung nodule for tuberculosis. It was a time of fear and a time of hope. Fear that things would not go well and hope that his health would be much improved. He came through a 4.5 hour operation and my family and I were relieved when it was over. He was in the hospital for a week, and then allowed to return home.

My enthusiasm was unlimited. I was full of hope and energy for his recovery. He was in a good deal of pain and it took about three months before he was able to go out. Our first trip was to the clinic for blood tests. I had banking to do, so I left B. at the clinic with the idea that we would meet at a local coffee shop in our neighbourhood. I waited at the coffee shop, and - no husband. I went to look for him, finding him looking for me. He had forgotten where the coffee shop was. I had a sinking feeling things were not right.

This began a series of mental evaluations. After a number of tests, the conclusion was dementia. Something happened during surgery. A stroke or lack of oxygen to the brain. From then on things changed.

He became disoriented and I lost him many times. At the shopping malls, at the airport, in hotels. He could not remember things and the loss of short term memory was evident. Once an outgoing personality, he was withdrawn and quiet. He was a professional carpenter and painter. Now performing familiar tasks was difficult. He remained easy to get along with and was never aggressive.

Finally, after looking after my husband for 7 years, I ended up in the hospital. Finding nothing physically wrong, it was concluded that it was a stress related problem. I had continually refused long term care for him. Finally, because of my health, I had to make the most difficult decision of my life. Long term care for my husband. He has been in for nearly three months. I bring him home every weekend and sometimes during the week. His one question is “When can I come home?” I hope if I get feeling stronger I can have him home again.

We have been married 58 years. I feel empty inside. Perhaps his memory being less sharp is a blessing. He is not thinking about things the way I do. I am thankful he is still here.
The Two of Us

Where do I begin? What do I say? Our life began together 60 years ago this month. Just a bit of background: We were married in London, Ont. March 28, 1941. Right from the start we were committed to one another. He is the only love of my life and the same for him. Our only separation was through the war years: We built our lives together; we stayed together, played together and prayed together. Then there was the family. 5 children, now 17 grandchildren, 11 great-grandchildren. With the usual ups and downs and in and outs of raising school children - then teens - the bills, the housing and some very serious illnesses. My husband was a very quiet, conscientious and faithful worker - and husband and father. I depended so much on his wisdom, kindness, patience and love. Together we weathered lots of storms. But it was 2 of us.

I first noticed a complete change in my husband's personality 3 years ago. He became irritable, suspicious, forgetful, very agitated at me with no motivation. He had loved his computer and just wouldn't use it. He started pacing back and forth, back, forth. Never sitting for 2-3 minutes. I finally took a list to the Dr. of all the changes. Over a period of time and tests he was diagnosed with "Alzheimer's Disease". I was completely devastated.

We took time out to go to Hawaii with our daughter and son-in-law. All the time before, one minute he'd go, the next he wouldn't. We did finally get on the plane. About this time I was becoming exhausted and nervous. My husband's actions and attitudes were unexplainable. He started picking fights and accusing me of having an affair. On the flight home he was so agitated my son-in-law could hardly hold him down. We landed safely but R. drove him right to the Hospital from the airport. The poor man was so sick. I'm not going into the dreadful details when they locked him up in a Psychiatric ward. I was devastated. I told them "He has Alzheimer's Disease. He doesn't need to be locked up." After much protesting, they moved him to the evaluation ward.

What a Christmas that was!

When he came home he started pacing back and forth, in and out of the apartment. Never sitting down for meals for 2 minutes. We stopped socializing. I had to run after him because he wandered away. I was totally exhausted. It seemed to me our lives were falling apart. I was so nervous and frightened, and cried all the time. I couldn't go out and leave him alone. If I took him with me, I was constantly watching him in case he wandered.

I couldn't focus on daily tasks for living. The poor man was so sick, and I was so exhausted, I was no help.

In the meantime my Dr. sent me to the Counsellor, and the geriatric Psychiatrist. I thought I'd never need a Counsellor, but I am so genuinely grateful. This (caregiving)
is something I had to face alone, just I. I was frightened and scared. I can't express how much everyone helped me (especially the Counsellour). Week after week she listened to me. She connected me with all the right people. She'd be there for me, make a lot of personal calls to my house. The Dr. too.

Because my husband was not competent to be handling the finances, I'd never done it before - he left me in a mess. So the Counsellor stepped in again. Sent in a Financial Counsellor to help me straighten things out. I was like a zombie. I couldn't focus properly. I think they were beginning to think they had 2 seniors on their hands instead of one. She made all the arrangements to put F. into the Respite Centre, and also the local Friendship Centre 5 days a week. But eventually he began to try to wander away there too and paced back and forth disrupting the program.

Then I was approached or advised to think about placing my husband in a home care facility. Its hard to put on paper the emotional stress; the denial, the crying, confusion, pain, arguing, yes even fighting at times, then the love and forgiveness, the loneliness, the family denial, crying out to God "Why us!" Then blaming God, even cursing him. Then find forgiveness and peace in the solitude of God. Having to take hold of our lives and situation. Without my husband beside me. No communication. Every thing just went over his head.

I can't tell you how I felt - I rejected the idea. I dreamed about it. The loneliness and responsibility it put on my shoulder. I was overwhelmed. The crying began again. I cried: on the bus, on the street, in stores, in company, and alone. I was totally exhausted. I listened to Nancy Reagan on the Larry King show. He ask her how she felt when Ronny was diagnosed with A.D. She said "If you've never gone through the deep emotional mixed feeling of having your partner no longer able to communicate with you I can't express it and nobody really understands the emotional feelings."

Well, the Caseworker came to the house. I called my sister to be with me. She said there was room right now at C. residence available. If I turned it down I may have to wait a long time. Because it was the weekend, they said they'd wait 'till Monday. I put F. in the Respite Centre so I could think what I was doing. Was this the right thing to do? I began to feel guilty and wondered if I could really do this. It was a major decision - a nightmare.

On Saturday morning I got up and thought I would go and get a few groceries. Well, I tripped, fell, and in a moment's time - things changed. I was whisked off to the hospital to find out I had a very shattering fracture to my left wrist. I was a basket case. I was worried about my husband. What would happen? I had to pick him up at 8am Sunday morning. I cracked up again. Well my operation revealed I'd have to have bone grafting from my hip and a plate and screws put in my arm. Then a cast. Well I broke up completely. When will I ever stop crying? There again, I contacted my daughter and the Counsellor. She came and arranged for my husband to stay at respite 'till the Wednesday. Then, on Wednesday, my daughter and the counsellor got his
necessary clothing and took my husband to his new address. He was told the circumstances and patiently went with no fuss. Well I had a 10 day stay in the hospital and had help at home. I had a cast for 3 months and then physiotherapy. So, it was a good transfer. As long as I had the cast on my husband was content. He realized I couldn’t look after him and so he settled in.

I was amazed and thankful how God had intervened with all this. I was so weak, dreading the move. It was all done for me.

He has been at the residence for 1 year now. He is doing well under the circumstances, with proper medication and good care, regular meals and no responsibilities. He is in a constructive environment. He knows he yet and depends on me. There is very little communication on his part, but I go 3-4 time a week and chatter away to him, take him for walks, dinners, join him when I can in the activities at the Residence. We play a card game he enjoys. He is happy in his own world.

I miss the communication we had. To talk about things that mean something only to we two.

I bring him more periodically. The last time he was home, he went to bed easily. When I crawled in I snuggled up to him and wrapped my feet around his. There was no response (I’m not talking about sex). I asked him to turn over and snuggle me up. I needed to be hugged. His arms fell listlessly over me. I miss him so. He does still tell me constantly he loves me. I cherish this even though the physical snuggling is not there.

I’ve been to quite a few Caregiver courses and Alzheimers meetings. I read all the literature I can. I have been told what to expect in the future. What can I do? I quote Nancy Reagan again. “You give all you can and get nothing in return, but you do it cheerfully because of love.” As someone in the group said last week “Remember, he had a good life and did all the things he wanted to do. Went where he wanted to go. He was and is a good Husband, a good Provider, and a good Father. All round you have lots of happy memories.” The children are very supportive now. I’m making an album for him of all our anniversaries - just we two. I know he’ll enjoy it. My gift to him.

What do I do now? I have to keep going. Get up and face the day.

Wait.
**Caregiver at Heart**

When the strokes started we didn't know how serious it was at first. Little by little my husband's health deteriorated as the years went by; 7 years in all. My goal was to care for him as well as it was possible. And my hope was that maybe the illness would even go away. We were praying a lot. However, it was wishful thinking. Gradually he got more ill.

We immigrated to Canada in 1951 from Finland as a young couple. We established our life here in Vancouver B.C. Our 2 children were born in the years following. My husband had a good, steady job at Westinghouse. He was always very healthy; never missing work because of ill health.

When the illness started, I realized that something was seriously wrong, but my husband didn't. I first noticed when he kept on falling out of bed. These were the strokes. He said he felt that something was pulling from his head. Always being so healthy, it was difficult for him to accept that he was ill. He went into denial.

One Sunday morning, he wasn't able to get out of bed. I called the ambulance and he was taken to the hospital. But, you see, by that time it was too late. The strokes had been going on for some time. It was too late to try to prevent them. After that, the caregiving really started.

My husband began to use strategies to cope with losing his memory. He would make notes for himself and mark the keys in the house so he would remember what they were for. Being an independent person, he wanted to manage things himself. Especially when it came to finances. He couldn't write a cheque at one point, but he tried anyway. We got into struggles. This caused me a lot of frustration. He wanted to be in control, but he wasn't capable of doing it anymore.

At the hospital he was diagnosed as being a diabetic. At the Doctor's request he also attended a research group for a new medication for dementia. He went once a month until his memory was so gone that there wasn't much point in testing him anymore. This was over several years. At first the medication helped, but the improvement only lasted about 4 months.

The illness got to the point where I could not care for him alone anymore. I needed help. I was able to get him into a Daycare 3 days a week. He could not be left alone anymore. He wasn't aware of what he was doing. The Government allows 4 weeks of respite a year. I took advantage of this. Going to respite helped my husband get used to being in a care place. This helped tremendously when he ended up in a care place permanently.

As a Caregiver, I started to realize that my strength and energies were used to the max. But somehow each day I had the strength to cope with all of the problems. One
of the problems was that he became incontinent. This was another battle, because he fought me when I tried to help him. It was a mess.

A bed opened up for him in a care place. I had him admitted for the first time. It was a devastating experience. I felt that someone had pulled the arms off my body. It was terrible. The separation was terrible. And the feeling of hopelessness, knowing that he would not be coming back. However, after 3.5 months I decided to bring him back home, because there were things happening at the care place that made it a bad experience. The attitude of the staff was that they owned my husband. They actually said “We are his family and this is his home.” I strongly disagreed.

I knew I would have a very hard time, and didn't know how I would cope, but nevertheless I took him home again. I was able to get him back to Daycare, and I also used a weekend respite program. So I was able to sleep 2 nights a week. He would only sleep 2 hours in a 24 hour day. His heart was failing, but we didn't know.

Gradually, I knew I would collapse if I didn't get him admitted. I got an emergency bed at a care centre. It was a very good place. There the Doctor discovered that my husband's heart was failing. The medication he was given helped with this. I still went there most days to feed him and take him outside. He loved the outdoors. I could tell he knew when we were outside.

After he went into the care place I began to grieve the experience. When you are so busy you don't have time to grieve. Now I had time again. It was very hard getting used to being in a house all alone.

Now that I was also able to sleep my nights I became more like myself. I was more calm. I could get my thoughts together and concentrate.

I was able to spend quality time with my husband. I would take him to the roof terrace of the care home. We watched the sunset over the Northshore mountains and the birds returning from the sea. I used to pray with him and sang his favourite hymns. It was a great blessing to him. Those were the precious moments of caregiving.

At some point, due to the diabetes, his foot split open and it became infected. There was a threat of it being amputated. That was a nightmare. I asked the church congregation to pray. The foot gradually healed. All the Doctors said it was a miracle.

In 1950, when we got married we used to laugh about seeing the year 2000. It seemed like 1000 years away. When the year 2000 arrived, I was there with the whole family. I said “It is the year 2000. We made it to the year.” He seemed to understand. However after 18 days, on January 18th, he passed away, so we didn't make the day of our 50th Anniversary.
The day that our 50th Anniversary would have been, I went to the grave site. I placed a red rose on his grave. I thanked God for a marriage that lasted a lifetime.

The caregiving ended when he died. Up until that point I would bath him. I felt needed. After he died, I was thrown into a different kind of grief; where there was no caring, or loving the person, or being needed. The most difficult year of my life started. It was very painful.

I went through the stages of grief in a grief sharing group which was a great help to me and my recovery. A Bible verse kept coming to mind “Weeping may enter for the night, but joy cometh in the morning.” Now life and joy has started to come back to my life. I am engaged to be married again.
Appendix E: The Collective Narrative of the Support Group

As A Caregiver, I

A researcher met a caregiver one day. She, as a caregiver, had come to a research group of like-minded people to share her knowledge of caregiving. The researcher said "I must hear your story. I can learn from your wisdom and experience. And it may do you well in the telling." The caregiver looked at her colleagues in the small room around her. They looked back from their circle of chairs. She took out a few crisp white sheets of paper with dark print. She said "I will share my life as a caregiver. It has been a challenge in the last few years. In my sharing you may gain insight and you may understand." And she began:

Being Part of the Group of Caregivers
What I tell I want to be real. What does that mean? To make general descriptions while still knowing that each day is different and each individual changes. To write in a way that is respectful and has the dignity we deserve. To acknowledge the complexity of the experience. Some experiences I describe have a big impact, and some are part of the everyday. I want to share a story about life; work and relationship, growth and death. Those are the elements of life.

Maybe by talking in the group, and writing for myself, we could just put things into a different perspective, have a few more choices and live with some of this in a new way - new possibilities.

When I was approached to be part of this study, I thought, "Well I have been a caregiver, but what do I really have to say?" I wanted to know more about the experience, and I wanted to learn how to better get on with living my life. I had my own reasons for being in the group. I wanted to connect with other people in the same situation. I wanted to use this as a chance to deal with the grief of my loss so I can go on with my life. I wanted to figure out how to handle the helplessness, anger and other emotions that influence my day in relation to being a caregiver.

How did you deal with it? How did I really deal with it? At first, it kind of just happens to you, and although you work hard emotionally and physically it has a life of its own and you live with it. IT is the position of living with someone with dementia. That someone is a close family member of mine. For me, the person was my husband. For some of my acquaintances the person was a parent. In either case, the relationship has a history of communication and support. These patterns were forced by dementia to change. It becomes more one sided. I cared through the
change. What did I get out of it? Why did I do it? These were questions on my mind.

The Meetings
At the first research meeting, I wondered if this was going to work. Who are all these other people? How much can I really talk. They were strangers with only one thing I knew we had in common. We were Caregivers - a label that some people take and some people reject as a part of themselves. I am a Caregiver. I have cared for my family and for my husband for many years. A lifetime. But I will talk more about that later. I notice, I don’t usually use caregiver as a description of something I do for myself. So we were sitting together in a comfortable room. I was interested in meeting the other four people. I was not sure if the question from the researcher would be too intrusive, too personal, but we could decline to answer if we wanted to. It began with rules about how the group would function and then we were into introductions. Each person said something about who they were. Suddenly, as I heard about the others lives and families, I almost forgot that they were strangers. We had so many experiences and feelings in common. The conversation was lively and I felt connected.

We were asked to write our story down. Write it down! That sounds like homework. I hadn’t done something like that for a few years. Somehow putting my story on paper seemed daunting. I thought, “Where should I start? What do I include? Will it be complete enough, important enough, good enough?” It took a few deep breathes and a mental leap to get started. I wanted it to mean something. Stories are a natural way to make sense of things. People have used stories to be known and to teach for a long time. Sharing our stories was a concrete way to both support each other and to make sense of who we are as caregivers. This included what meaning this has had for me, where I have been at and where I want to be. So I wrote my story.

Then we were asked to bring the stories to the group and read them to each other. Two stories each week. Reading mine was a little scary. It’s kind of like being more exposed. Its a bit of a risk. I had the story ready before hand, but to read to the group made me open to their judgment. I was a bit nervous while I read. When I finished, there was a moment of silence. Then people gave me ‘feedback’ - their impressions, and things that really stood out for them. They said things like: “You have put a lot of time and energy into being a caregiver in the last few years”; “You handled that situation very well”; “Your ability to laugh is a great personal ‘resources’.” It was sometimes surprising what people saw in my story that I had not recognized, and it felt good to have people acknowledge what had
not been appreciated much before. They could relate, because they had been in a similar situation.

The rest of the time in the group was spent talking about topics that came out of our conversation. Some of the topics were things from the past, and some were things that were happening now. It was helpful to talk about it and to get other opinions. We had enough trust that we could give each other different perspectives. I, for example, felt sad that my husband did not have much ability to do things anymore, but one other group member pointed out that my husband had accomplished many things in his life before the illness. When I saw that longer perspective it was easier to feel better. It was both a frightening thought and a relief to hear that things change as time passes. It was a relief though, that I am not alone in having this huge range of feelings (guilty, frustrated, helpless, love). I had a lot of ideas about how things "should" be, and the situation didn't always allow that. I am still making adjustments on all kinds of levels, like: my emotions, physical being, and life direction. The group discussion was information for that adjusting process.

When My Turn to Read in the Group Came Up, This is the Story I Shared with the Group

My husband and I have been together for 55 years. We raised children together. We were only separated during the war years. We built a life together. There were countless nights when we lay in the same bed and held each other's hands or entwined our feet. I felt like he knew me so well. My moods, my strengths and weaknesses, my preferences. We had our ups and downs like everybody does. We supported each other most of the time.

He was a hard worker. He had a career. There is a certificate above his bed which states how competent he was at his job. He was a strong, independent person who had a real impact on his world. There were many things I admired about him. That competence changed drastically. He remained competent at living in his room and getting exercise. He could be kind and listen. He was competent at enjoying the games we played or the walks that we took. He had moments when he remembered the names of the people in his life. Moments of clarity. Of course, I worried what people would think. Most of the time, I knew he was still a worthwhile person. It took a while to accept that he had lost his ability to do things. A friend of mine said 'Others understand, but we are hardest on our own'. Like when I was embarrassed that he spilt his food in a restaurant when we went out to eat. How much do our outward appearance and our abilities determine our worth?
The Diagnosis and Changes In Life at Home
At first we did not recognize the dementia for what it was. His behaviour changed. He was not interested in the things he used to really like. He was more moody than before. He could not take care of the finances, or look after the physical things in the house. Every moment was a change in his ability and behaviour. I was not sure what to expect from one moment to another. After the diagnosis, at least I had an explanation. That was a relief.

Eventually his behaviour completely disrupted my life. He would wander all the time. He couldn’t sit still. He lost his appetite. He could not remember things and would ask the same question every few minutes. Sometimes he would be aggressive or afraid. He started to see people in the house or he would accuse me of things. He did not always want my help; although he became incontinent and couldn’t bathe himself. We fought. I couldn’t get any sleep, because I had to keep an eye on him. I became more and more exhausted. We stayed home more and more. We saw people less. It was lonely. I felt isolated. I learned to completely look after the house and to look after my husband. I learned about the disease and the medical system. I became more independent than I have ever been before.

Reaching Out for Help
Then I started to connect with family and outside support services. I had a very helpful social worker who listened to me and told me about available services. She was a big help in arranging things. I arranged to have home support come in to the house for 2 hours a week. That was a mixed experience, depending on the person who came. It is hard to trust someone in your personal space, and to accept help in your home. One person tried to steal from us. After that I cancelled the home support.

I did arrange for my husband to spend 2 days a week and the occasional weekend in a respite facility. That was important time for me. I had a chance to get some things done around the house. Mostly the time allowed me to recover some energy. Sometimes I would get together with friends.

I also had the support of my faith. I could not have handled all of this without knowing God was there with me. I prayed for strength. I felt less alone. In one church I went to, people from the community called me every week. That was a help.

I was very grateful that I had family (my children and several siblings) to come over and help. I didn’t want to tell them everything, though. There was something personal and private about it that I did not want to share. I
did not think they could understand; especially since when they came to visit, my husband often seemed better than what I thought he was. They say the social graces are the last to go.

Leaving Home
I wanted to keep my husband at home with me as long as possible. It was still our life together. I couldn't bare being the one to end that. Besides, I thought going into a care facility might mean a low quality of life. It was also a matter of his dignity. People lose a chunk of their independence when they move into a place like that. I knew, that strangers could not care for him as well as I could. I just knew him better.

When I did start looking at care homes, I felt really ambivalent about the whole process. I found out it was important to visit the places first. Different facilities offer different things, and some of them are happier, cleaner, better staffed, or have more programs than others. I knew you had to be put on the waiting list, but I was not ready for him to go. They could call anytime to say a room was available. Then we would have 2 days to move him out of the house and into the room. The thought of it made me sick.

Eventually, it was my Doctor who told me I couldn't look after him anymore. I was getting heart palpitations, and I couldn't lift him. Having 2 sick people on our hands was not a good idea. I felt sad and helpless. And I felt so guilty. I was desperate that I couldn't do enough. I was angry that he could not communicate with me, that he wanted things from me, that he had left me to deal with all this. I was dealing with a slow deterioration and continuing loss while still working for him/us. Although I knew things like this could happen in life, having to separate like that was not how it was supposed to be for us. I had professionals encouraging me to do something I completely dreaded.

When the time came for him to leave, it was very sudden. It was the hardest decision I think I have ever made. He was gone from our home. The room at the care home came open and I had to accept it. If I did not, the alternative was that I would lose my space on the list. This in turn would mean that if something happened to me, my husband would be put in an emergency bed at the hospital and later sent to the next available long term care bed in the city. I would have no control over where he ended up. So I took the bed that came up, or rather I accepted it for my husband. Now, after caring for him day and night, he was gone. I felt like someone had torn off a part of my body. I had never felt such intense grief. I questioned myself.
I was lost. I thought, "Who am I now that I am not in the same relationship to this person? Am I the same person? Am I different? I am no longer a wife who has a supportive husband. I may know he loves me, but I am only thinking it, because he can't show that emotion any more. - Sometimes he is appreciative, sometimes he does not like things. - How much of me was a mixture of me and him (was us)? - What do I do with myself now? I give a lot of energy to care for him, arrange things for him, and understand his needs. - The things that define me have changed somewhat. I am not really part of a couple anymore. Many of the couple friends we had have drifted away. I relate more to 'single' people now. - I am not the wife of a competent man. - I am not able to spend as much time doing things for myself, or make plans for the future." I spent a lot of time thinking about it.

To top it off, after my husband moved, he did not like the room. He did not want to move. Every time I went to visit - which was daily at first - he would ask me if I could take him home. It was hard to leave him. I was abandoning him, like he had abandoned me.

Living Apart
Over the next year, he started to get used to it. I went to visit often. I was still needed. I would bathe him or make sure he got a good meal. We took part in the social activities together. We both got to know some of the other people on the floor. He had his 'pad' and I had mine. I felt better now that I could sleep again. I had more time to care for myself. It was also reassuring to know that they had the equipment to look after him, at least physically, better than I could. He was safe. I have also heard since that it is easier for people to adjust and keep a good quality of life longer when they move into a care facility earlier, because the place is more familiar to them. Familiarity is important for people with dementia.

I started to think about things I would like to do for myself; go on a trip, take a dance class, volunteer, join a Bible Study. I still didn't always have the energy to pursue it. Sometimes I felt stuck and on hold. He was still with me in body, but he was not the same person I spent my life with before. All the plans we had made to do things together in the future were lost. My life still revolved around his.

I made sure I had positive quality time with my husband. We did things I knew he had always liked, such as watching the sun set. It became a different kind of life together. I still felt sad about how much we had lost. I still felt responsible sometimes. I still felt guilty if I couldn't give him what he wanted. I wanted him to be happy. It was a way we could connect. It was a way I could still have an impact. I found ways to keep up hope and be strong. His happiness was one of those ways.
The Final Loss
He continued to deteriorate. We waited. Sometimes I wished he would die; both for him and for me. Then, one day, it became clear my husband was dying. I watched him go. There was the funeral. I thought “I have really lost him”. He was gone both mentally and physically now. My days as a caregiver were really over. So I thought. I entered a period of grief that was even more intense than when he first left the house. I was really alone. The people who had called while he was alive, with a few exceptions, stopped calling. I got a new title; I was a widow.

I just wanted to get over the pain. Some nights it was unbearable, but I knew deep down that it was not going to kill me. I spent energy grieving the loss of the good parts of the relationship we had. I spent energy on the loss of the relationship we never had, but that I wish we had. I knew I had done all I could. I learned to make peace with myself and my experience. I joined a bereavement group. I wanted to express my self and my feelings. I wanted to grieve and get on with a new part of my life.

As with other parts of my caregiving experience, it was like rebuilding myself. I was using the same bricks as before, except that one important cornerstone was missing. I thought “How do you restructure without it?” But I slowly found a way. Through this whole process I have learned how to use my energy to become a caregiver to myself.

Meaning
Towards the end of our meetings, we, as a group, looked at the topics of the meaning of being a caregiver, and the identity of caregiving. First we created a definition of the meaning of this kind of Caregiving. Caregiving means showing my love and doing the best I can. It is about making sure things are as good as they can be. Why do I care? - because I love that person. It shows their worth.

Caregiving also means learning to be responsible for emotional and physical things I did not have to think about before. It means relying on myself, and finding the support I need outside of the caregiving relationship.

I also care because I need that person’s love. I have a whole history with them and it hurts when I don’t get that love anymore. That is the loss in this kind of caregiving, but feeling the grief and continuing to ‘be there’ is another way to love and honour our life together.
Self care: Caregiving for myself means balancing the family member's needs and my needs; with the family member's needs taking practical priority most of the time due to the illness. Caring for myself allows me to keep us living together as long as possible. That balancing is a choice. It is OK to do things 'for me' if I can justify it as helping them - there is a feeling that you can't do both. The group member whose husband had died, said that, in hindsight, she would take more time for herself.

Identity
We also created a definition of how the experience of caregiving changed (and didn't change) my sense of self. As a woman I have cared for people all my life. The kind of caregiving we were discussing is more time-consuming and intense.

It forced me to be more independent; looking after the household and personal well-being of two. I felt like orchestrator of our private lives at home and manager of public services to support me.

It made me aware of the extremes of my emotions and my physical limits. During this process I lived at an extreme, 'on-call', but it is still my daily life. Although I sometimes feel helpless, I am strong; even in surviving my emotions.

I felt alone. My social status changed. I was part of a couple without having the support of a couple, and I gradually made more single friends.

The roles in the relationship we had all along have changed. It is not as reciprocal a role. Or the role I always had is intensified. I plan my activities to practically support and to please my family member. It is not a starring role except that I have to be in control of what I can. I have to accept the limits of the person I love, and the limits of myself in loving them. This means that what I see as meaningful interaction and activity has changed. The happiness of my family member is central to my happiness.

The story of this research group came to an end. Writing my story did show me a few new things. It also, in some mysterious way, gave me a sense of closure (putting the experience in its place). I enjoyed listening to the people in the group and having people listen to me. I realized that I am a Caregiver among many and that it is part of my process of living. Caregiving includes continual learning and using all parts of myself. I am not happy that my family had to go through the experience of dealing with dementia. As a Caregiver, though, I can continue to show my love, do the best I can, and get on with my life.